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# Exploring the Mental Health Care Experiences of Youth Transitioning from Paediatric to Adult Psychiatric Services Using the Photovoice Method: A Participatory Analysis of the PhotoSTREAM Project

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Graduate Program in Nursing

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## ABSTRACT

The transition from adolescence to adulthood brings with it many new challenges and stressors that may negatively impact psychosocial wellbeing. Unfortunately, the disjointed progression from paediatric to adult psychiatric services leaves transitional-aged youth (TAY) vulnerable to its deleterious sequelae, including social isolation, self-harm, substance use, and suicidal ideation. As devised, the Canadian mental health sector is ill-equipped to meet the care demands of emerging adults, resulting in undue suffering. Current evidence validates the need for clinical practice reform and policy revision to address this issue, yet the perspectives of young people are consistently underrepresented in conversations regarding youth-oriented psychiatric program development, despite a desire to share their personal narratives.

This paper describes the findings of a youth-led participatory action research (YPAR) study conducted in London, Ontario, Canada. An acronym for *Supporting Transition-Readiness for Emerging Adults with Mental health challenges*, the PhotoSTREAM Project explored the perspectives of eight TAY (aged 18-24), who progressed from paediatric to adult psychiatric services within the province of Ontario. Through a combination of photography, focus group discussions, and individual interviews, the Photovoice method was employed to illuminate TAY interactions with the mental health system during this period of transition; thereby, highlighting the strengths and shortcomings of existing policies and practices that impact quality and continuity of care for this age demographic. Insights gathered using this collaborative, participatory, and action-oriented research framework contribute to an enhanced awareness of psychiatric service delivery gaps experienced by emerging adults, and advocate for seamless and supportive transitions that more effectively meet the needs of the TAY population.

**Keywords:** mental health, transitional-aged youth (TAY), emerging adult, transition, nursing, participatory, youth-led participatory action research (YPAR), youth engagement, photovoice

## **SUMMARY FOR LAY AUDIENCE**

The transition from adolescence to adulthood brings with it many new challenges and stressors that may negatively impact mental health and wellbeing. Unfortunately, the disjointed progression from paediatric to adult psychiatric services leaves transitional-aged youth (TAY) vulnerable to negative consequences, including social isolation, self-harm, substance use, and suicidal ideation. As devised, the Canadian mental health sector is ill-equipped to meet the care demands of emerging adults, resulting in undue suffering. Current research validates the need for clinical practice reform and policy revision to address this issue, yet the perspectives of young people are consistently underrepresented in conversations regarding youth-oriented psychiatric program development, despite a desire to share their personal narratives.

This paper describes the findings of a youth-led participatory action research (YPAR) study conducted in London, Ontario, Canada. An acronym for Supporting Transition-Readiness for Emerging Adults with Mental health challenges, the PhotoSTREAM Project explored the perspectives of eight TAY (aged 18-24), who progressed from paediatric to adult psychiatric services within the province of Ontario. Through a combination of photography, focus groups discussions, and individual interviews, the Photovoice method was used to illuminate TAY interactions with the mental health system during this period of transition; thereby, highlighting the strengths and shortcomings of existing policies and practices that impact quality and continuity of care for this age demographic. Insights gathered using this collaborative and action-oriented research framework contribute to an enhanced awareness of psychiatric service delivery gaps experienced by emerging adults, and advocate for seamless and supportive transitions that more effectively meet the needs of the TAY population.

## **CO-AUTHORSHIP STATEMENT**

Brianna Jackson conducted this research under the supervision of Drs. Richard Booth and Kimberley T. Jackson of the Arthur Labatt Family School of Nursing at Western University in London, Ontario, Canada. Their contributions will be recognized through co-authorship on any publications resulting from the enclosed manuscript.

## **DEDICATION**

This work is dedicated to the many transitional-aged youth living with mental health challenges, who feel silenced and unsupported as they navigate complex services and systems. I am in awe of your unwavering strength, determination, and resilience in the face of such adversity. The paths you have forged will effect transformational change for those who follow in your footsteps. May you find meaning and validation in your experience.

- To the eight participants involved in the PhotoSTREAM Project, I sincerely thank you for your curiosity, your enthusiasm, and your candour. Your stories have left me both humbled and deeply moved. I am optimistic that the insights you have shared will inspire hope for the emerging adult population.
- To the mental health allies and champions that dedicate their lives to the support and recovery of young people, your loyalty and compassion have left a lasting impression upon those you have cared for.
- Lastly, to the incredible community that ignited my passion for lifelong learning and advocacy, I am eternally grateful.

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## **LIST OF ABBREVIATIONS**

APA	American Psychiatric Association
CAMH	Centre for Addiction and Mental Health
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CMHA	Canadian Mental Health Association
CST	Critical Social Theory
FEMAP	First Episode Mood and Anxiety Program
HSREB	Health Sciences Research Ethics Board
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer and other identities
MHCC	Mental Health Commission of Canada
OCECYMH	Ontario Centre of Excellence for Child and Youth Mental Health
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
STREAM	Supporting Transition-Readiness for Emerging Adults with Mental health challenges
TAP	Transition Age Project
TAY	Transition(al)-Age(d) Youth
YPAR	Youth-led Participatory Action Research

## **CHAPTER I**

### **Introduction**

The transition from adolescence to adulthood brings with it a myriad of new challenges and potential stressors that may negatively impact one's psychosocial wellbeing (Baggio, Studer, Iglesias, Daeppen, & Gmel, 2017; World Health Organization, 2012). The process of physiological maturation — encompassing hormonal flux, neurocognitive development, and personality formation — when combined with role adjustments and external pressures, leave youth questioning their own identity and sense of belonging (Mental Health Commission of Canada [MHCC], 2016). It should come as no surprise then, that young people between the ages of 16 and 24 experience higher rates of mental illness than any other age group (Pearson, Janz, & Ali, 2013).

While biological transformations occurring during adolescent development significantly modify health trajectories, relational and sociopolitical considerations may play an even greater role in predicting mental health outcomes among youth (Yin et al., 2016). It has long been recognized that stability, consistency, and continuity in care delivery are of paramount importance for individuals with mental illness (Lindgren, Söderberg, & Skär, 2014; Tobon, Reid, & Brown, 2015); however, the disjointed progression from paediatric to adult psychiatric services leaves many adolescents vulnerable to its deleterious sequelae, including social isolation, self-harm, substance use, and suicidal ideation (Gandhi et al., 2016; Signorini, 2018).

### **Definitions**

Consistent with rigorous methodological practices espoused by Peters et al. (2015), the population, concepts, and context described below serve to frame the phenomena of interest explored by this research study. A scoping review of contemporary nursing and interprofessional health literature, which will be covered at-length in *Chapter II*, was conducted

based upon the following operational definitions.

## **Population**

*Transitional-aged youth (TAY)* — also referred to as *emerging adults*, *youth in transition*, or *youth aging out* — is a phrase commonly used to describe the age demographic spanning the nexus of adolescence and young adulthood (Wilens & Rosenbaum, 2013). While variably defined, *TAY* most often encompasses those between the ages of 16 and 24. Due to a complex interplay of intrinsic, socio-ecological, and broader structural factors, TAY represent a period of heightened vulnerability (Martel & Fuchs, 2017). Further obfuscated by a critical gap between paediatric and adult services across various sectors — including healthcare, labour, and criminal justice systems (Interagency Working Group on Youth Programs, 2018) — TAY are considered an at-risk population requiring tailored resources and supports (Centre for Addiction and Mental Health [CAMH], 2018). Throughout this paper, the terms *TAY* and *emerging adults* will be used interchangeably to describe young Canadians navigating this transition, as it applies to mental health and addictions services across the province of Ontario.

## **Concepts**

**Mental health challenges.** A contemporary phrase widely accepted within the psychiatric field, *mental health challenges* refers to negative thoughts, feelings, and/or behaviours that adversely affect psychological health and wellbeing (Hall-Flavin, 2016). For the purpose of this research, neither *illness* nor *disorder* are used to describe mental health status, as one may experience periods of emotional dysregulation or distress, perceptive or expressive abnormalities, and cognitive delays or dysfunction without meeting criteria necessary for a formal psychiatric diagnosis (American Psychiatric Association [APA], 2013). Mental health challenges may ebb and flow according to one's life circumstances and capacity to cope with stressors.

**Transition.** Health Quality Ontario (2012) defines *transition* as “a broad range of time-limited services designed to ensure healthcare continuity, avoid preventable poor outcomes among at-risk populations, and promote the safe and timely transfer of patients from one level of care, or from one type of setting to another” (p. 43). Within the context of this study, *transition* describes the progression from paediatric to adult mental health services across diverse institutional and community settings, and which provide care to individuals with varying levels of psychiatric acuity and complexity.

**Structural violence.** A term first attributed to sociologist Johan Galtung (1969), the concept of *structural violence* has revolutionized the modern discourse on health. Broadly referring to institutional policies and practices that cause harm, this lens differentiates intention from opportunity when considering systemic inequities that limit one’s capacity to engage in healthy lifestyle behaviours. Compounding oppressive forces impacting the accessibility and efficacy of psychiatric care for TAY widen an already precarious service delivery gap (Care Quality Commission, 2014). While potentially unsafe for anyone with mental health challenges, marginalized and underrepresented populations may face additional obstacles that threaten their wellbeing (Mikkonen & Raphael, 2010). Such injustice is often attributable to a pervasive emphasis on universality, as opposed to specificity, within the healthcare system (Mannion & Exworthy, 2017).

**Youth engagement.** Conceptualized as both a process and an outcome, *youth engagement* is the active participation of young people in planning and decision-making related to challenges or issues impacting their lives (Ontario Centre of Excellence for Child and Youth Mental Health [OCECYMH], 2016). While this often involves collaboration with adult allies, youth engagement necessitates that young people be regarded as equal partners and stakeholders in the pursuit of positive social change (Hamilton, Hamilton & Pittman, 2004). This principle

exists along a continuum, with varying degrees of youth power and influence, ranging from tokenism to youth-initiated and directed projects (OCECYMH, 2016). When achieved, youth engagement can foster a sense of personal meaning and purpose, as well as broader community ownership and belonging (MindYourMind, 2015). The study described in the forthcoming manuscript used participatory approaches to enhance youth engagement in the research process.

## **Context**

This research study took place in London, Ontario, Canada — a mid-sized urban centre with considerable ethnic diversity and socioeconomic variability. This city has a high proportion of young people who fall within the TAY demographic, owing primarily to its two large academic institutions. Home to Western University and Fanshawe College, London welcomes a combined total of approximately 60,000 post-secondary students each school year (City of London, 2019). Considered a major healthcare centre within the province, London boasts a large number of acute care facilities, as well as community agencies. In recent years, a growing number of targeted mental health services specific to the TAY population have emerged, including: the mental health care Transition Age Project (TAP); the First Episode Mood and Anxiety Program (FEMAP); crisis assessment services available on college and university campuses during periods of heightened stress; as well as several youth advisory committees and advocacy groups managed through non-profit organizations such as the Canadian Mental Health Association (CMHA) of Middlesex, MindYourMind, Youth Opportunities Unlimited, Addictions Services of Thames Valley, and the London Community Foundation.

Unfortunately, demand for TAY-specific mental health supports continues to increase, while London's social service infrastructure remains disjointed and overstretched (CAMH, 2019). Grant funding for the TAP ended in May 2019, requiring valued resources such as the Cornerstone Counselling Program — a free, same-day appointment, and open-referral mental

health and addictions counselling service for emerging adults — to close their doors (London Community Foundation, 2019). Current treatment wait times for FEMAP exceed 12 months, following an initial intake appointment occurring nearly 4 months post-referral (London Health Sciences Centre, 2019). Meanwhile, suicide rates among post-secondary students in the City of London have reached an all-time high, despite on-site counselling and crisis services (Canadian Broadcasting Corporation News London, 2017). While youth who participated in this study may have received mental health care anywhere within the province of Ontario, recruitment targeted young people currently residing in London or surrounding rural municipalities of Middlesex County.

## **Background**

As currently devised, the Canadian mental health sector is ill-equipped to meet the care demands of TAY, resulting in undue suffering (Martel & Fuchs, 2017). Not only is this population underserved, but the limited treatment and intervention programs offered also seldom reflect the unique challenges of this cohort as they enter adulthood (Office of the Provincial Advocate for Children and Youth for Ontario, 2013; Shah & Boudos, 2012). Despite widespread acknowledgement of this problem by political leaders, healthcare providers, and the general public (Hovish, Weaver, Islam, Paul, & Singh, 2012; Singh et al., 2010), youth remain unsupported by the very system intended to promote their wellbeing (Amarthey et al., 2017).

While consistently cited as a government priority, lack of mental health funding is a pervasive issue that greatly restricts the accessibility and comprehensiveness of psychiatric supports (MHCC, 2014). Of the \$53.8 billion spent on healthcare by the Ontario government during the 2017-2018 fiscal year, a disproportionate \$3.5 billion was shared among mental health and addictions services (Ontario Ministry of Finance, 2018). The overwhelming majority of this 6.5% budget allocation was directed toward acute inpatient psychiatric services, leaving

community resources without the funds necessary to provide effective and ongoing treatment and rehabilitation for those living with chronic mental health challenges (CMHA of Ontario, 2018). With 20% of Canadians affected by mental illness in a given year, government spending for mental health and addictions services must increase substantially in order to meet the demands of this growing disease burden (MHCC, 2017).

Circumstances are particularly dire for the TAY demographic, who fall to the bottom of the waiting list for adult psychiatric services on their 18th birthday — a critical gap which leads to treatment disengagement in 60% of cases (CMHA of Ontario, 2017; Davidson & Cappelli, 2011). Further contributing to this fragmented transition is the diffusion of responsibility for mental health policies and standards spread across seven government ministries, thereby resulting in poor communication and coordination of care (Kaufman, & Pinzon, 2016). For those fortunate enough to have received appropriate paediatric mental health services, patients are unlikely to be granted the same level and type of care post-transition, resulting in a loss of treatment protocol, trusted caregivers, and family involvement (Paul et al., 2013; Por et al., 2004). This is largely due to private insurance coverage limitations and ever-tightening exclusion criteria, as well as bureaucratic complexities that govern the availability of services across institutions.

### **Aim**

While the highlighted hegemony has led to devastating consequences for young people requiring psychiatric services, the limited qualitative nursing and interprofessional health literature available on this topic does not fully capture the impact of existing sociopolitical and institutional inefficacies upon the lived experience of those transitioning to adulthood (Cleverley, et al., 2016; Embrett et al., 2016). The voices of this vulnerable population are often silenced, leading to unfounded assumptions about service delivery gaps that have evolved through

peripheral observation and interpretation, rather than collaborative discourse and thematic analysis driven by participant knowledge and insight (Clark, Koroloff, Geller, & Sondheimer, 2008). Thus, the overarching goal of this study was to promote TAY empowerment and social justice, bringing to life Chinn and Kramer's (2008) theoretical concepts of praxis and emancipatory knowing. Such efforts serve to illuminate the experiences of youth transitioning from paediatric to adult psychiatric services — considering the various intrapersonal, relational, and contextual nuances that impact this transition — while also supporting a collective youth vision for optimal mental health care at this nexus.

### **Declaration of Self**

My personal affiliation with psychiatric services, as both a former client and current healthcare provider, has not only influenced my passion for mental health research and clinical practice, but has also heightened my awareness of systemic barriers and limitations to quality care. As a Registered Nurse working with both adolescent and adult populations across inpatient and community mental health settings, I have witnessed firsthand the devastating consequences of poorly coordinated care for TAY entering adulthood. Many young people *fall through the cracks* during this critical developmental stage, losing contact with established therapeutic interventions and supports (Nguyen et al., 2017). Unfortunately, available treatment options do not adequately replace the comprehensive paediatric services to which youth have become accustomed, resulting in frustration, withdrawal from psychiatric rehabilitative practices, and an increase in maladaptive coping and health risk behaviours (Embrett et al., 2016).

Despite challenging circumstances during my upbringing, I believe the kindness and support of allies within my community played an instrumental role in my personal growth and development, and ultimately gave me the strength and determination necessary to overcome incredible adversity. While perhaps unfortunate, my unique childhood experiences have left me



deeply invested in the study of youth mental health and have informed my critical perspective of this complex topic. As a psychiatric nurse researcher, educator, and advocate, I hope to effect meaningful change through collaborative inquiry and praxis, thereby positively impacting the lives of those experiencing mental health challenges.

### **Significance**

While the period of transition between adolescence and adulthood, and its associated challenges are anything but new (Mandarino, 2014; Schulenberg & Schoon, 2012), the unique psychiatric care demands of this population have only recently gained traction among health researchers and practitioners alike (Wilens, & Rosenbaum, 2013), with a significant majority of studies conducted within the last five years. However, despite the growing body of evidence in this field, such needs have yet to be formally acknowledged and prioritized by the prevailing social and political institutions ideally positioned to address them (Evidence Exchange Network for Mental Health and Addictions, 2016).

If we are to truly enhance the psychosocial wellbeing of this at-risk population, health professionals must look to innovative and novel approaches to promote the rehabilitation, recovery, and resiliency of young people (Hart & Maslow, 2018; Viner et al., 2012). As trusted clinicians and coordinators of care, nurses are uniquely positioned to advocate for the needs of youth transitioning to adulthood through direct patient contact across the care continuum (Kalinyak, Gary, Killion, & Suresky, 2016a; Moynihan, Saewyc, Whitehouse, Paone, & McPherson, 2015), and thus have the capacity to influence meaningful systemic change for this demographic (Fontana, 2004). Through critical analysis of oppressive institutional protocols, Youth-Led Participatory Action Research (YPAR) serves as an incubator for awareness and advocacy that has historically led to significant policy reform and clinical practice revisions (Ozer, 2016). This action-oriented framework has been utilized in the following research study

to facilitate collaborative inquiry, investigation, dissemination, and reflection (Ohmer, Sobek, Teixeira, Wallace, & Shapiro, 2013); thereby, illuminating youth perspectives and eliciting meaningful discussion regarding the strengths and shortcomings of existing mental health services, and opportunities for more seamless and supportive care transitions that bridge the gap faced by Canada's emerging adults (Ministry of Children and Youth Services, 2012). *Chapter II* delves deeper into nursing and interprofessional health literature exploring the intersection of TAY, mental health, and participatory research approaches such as YPAR. A lack of evidence in this arena has served as the impetus for the described research study — the methods and findings of which will be detailed in the manuscript that follows.

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## CHAPTER II

### Problem

Adolescence is a tumultuous time, riddled with stress, confusion, and uncertainty (Sukhera, Fisman, & Davidson, 2015). While this anxiety-inducing, hormone-fueled experience of maturation has persisted throughout history, evolving social conditions have significantly altered traditional life course trajectories and timelines (Salvatore, 2018). Whereas the onset of puberty clearly demarcates one's departure from childhood, the culmination of adolescence is far more ambiguous — complicated by compounding behavioural, relational, and cultural influences (Stambler, 2017). Given the increasing social complexity of modern civilization, 21<sup>st</sup> century youth are *growing up* at a slower pace than ever before (Mirjana, Kirsch, & Skehan, 2016). Presented with extended life expectancies, competing priorities, and greater opportunities for advancement, today's generation reaches important milestones such as financial independence, career initiation, home ownership, marriage, and child-rearing, several years later than their predecessors (Mandarino, 2014). Historically inaugurated by one's 18<sup>th</sup> birthday, adulthood coincides with the acquisition of expanded legal rights and societal responsibilities (Davis, 2003). Unfortunately, the wisdom and confidence necessary to navigate the challenges concomitant with this transitional period are acquired gradually over time, and seldom align with inflexible, socially-constructed age classifications (Mandarino, 2014). As such, awareness and acknowledgement of *emerging adulthood* as a distinct age categorization spanning 16 to 24, has been popularized organically (Salvatore, 2018).

An abrupt shift in biological, psychosocial, and functional development corresponds with an increase in mental health challenges among transitional-aged youth (TAY), with the initial presentation of psychiatric symptoms occurring before the age of 25 in 75% of cases (Carver et al., 2015). Such heightened vulnerability during an already chaotic time period for emerging

adults, can often lead to acute episodes of mental health crisis, and engagement in maladaptive coping behaviours, such as criminal activity, risky sexual practices, substance use, and self-harm (Salvatore, 2018). Tragically, suicide remains the second leading cause of mortality among TAY in Canada, surpassed only by accidental death (Navaneelan, 2017).

Treatment-naïve youth who experience the onset of symptoms related to psychosis, mood, anxiety, or personality disorders during the transitional period, often *fall through the cracks* due to the absence of targeted mental health assessment, intervention, and rehabilitative programs tailored to the unique needs of the emerging adult population (Jabbour et al., 2016; Munõz-Solomando, Townley, & Williams, 2010; Ousch, Vingillis, Fisman, & Summerhurst, 2016). Equally impactful, a lack of coordinated psychiatric services bridging paediatric and adult care realms leave those diagnosed with severe mental illness during childhood, uninformed and unsupported as they embark upon a daunting transition (Klodnick, Davis, Fagan, & Elias, 2014; Sukhera et al., 2015).

This disjointed service progression leaves many TAY with mental health challenges feeling overwhelmed and ill-equipped to cope with the increased demands of adulthood independently (Mandarino, 2014). Role confusion, obscured identity, and a lack of self-efficacy at this nexus may stunt one's psychosocial development, ultimately contributing to reduced quality of life, and poor mental health outcomes across the lifespan (Davis, 2003). In contrast, a study by Haber, Karpur, Deschênes, and Clark (2008) revealed that improved psychiatric care transitions for emerging adults predict greater educational advancement and increased employment rates; thereby, contributing to enhanced personal freedom, autonomy, and self-sufficiency. Such findings validate the concept of *developmental cascades*, suggesting that one's level of functioning during formative years significantly influences that of future life stages (Lewin-Bizan, Bowers, & Lerner, 2010). Left unsupported, mental health challenges during the

transitional period may pose an insidious and pervasive threat to one's individual and interpersonal health and wellbeing over the long term (MacLeod & Brownlie, 2014).

A foundational understanding of current, best evidence related to the phenomena of interest was required prior to initiating study-related procedures described in the *Methods* section of this chapter. Through critical reflection, discourse, and analysis, the enclosed research sought to gain an enhanced understanding of TAYs mental health care experiences during their progression from adolescence to adulthood. Using participatory research methods rooted in principles of youth engagement, TAY insights into the strengths and shortcomings of existing transitional psychiatric supports not only illuminated mental health service delivery gaps, but also revealed novel solutions and opportunities for transformational change. In order to effectively meet the psychiatric care needs of emerging adults with mental health challenges, TAY, caregivers, healthcare providers, researchers, educators, and policymakers must work in tandem to effect meaningful clinical practice and legislative reform. Extending beyond traditional qualitative approaches discussed in topical nursing and interprofessional health literature, this study prioritized the opinions and perspectives of TAY as equal stakeholders and co-creators of evidence — respecting their knowledge, lived experience, and potential influence related to the intersection of mental health challenges and emerging adulthood.

### **Literature Review**

A comprehensive literature search of contemporary peer-reviewed scholarly works pertaining to the study topic was conducted to inform this program of research, guided by recommendations outlined in Peters' et al (2015) scoping review methodology. PubMed, Scopus, PsycINFO, and Nursing and Allied Health (ProQuest) databases were selected given the specificity of the study population, concepts, and context described in *Chapter I*, as keyword searches with Boolean operators more accurately capture the transitional nuance than broad

medical subject headings favoured in widely-utilized catalogues such as the Cumulative Index of Nursing and Allied Health Literature (CINAHL). Articles pertaining to the TAY demographic were broadly categorized in CINAHL under *Adolescence* or *Young Adult* subheadings — neither of which appropriately convey the uniqueness of the emerging adult age group.

Database searches were conducted to identify relevant journal article titles and abstracts containing the following keywords: (mental\* OR psych\*) AND (“transition\* age\* youth\*” OR “emerging adult\*”) AND (nurs\* OR health\* OR medic\*). Such parameters yielded a total of 694 records across the four databases, which were then screened for duplication and applicability. A rudimentary ancestry search was also performed, with reference lists of systematic reviews and meta-syntheses (Broad, Sandhu, Sunderji, & Charach, 2017; Cleverley, Rowland, Bennett, Jeffs, & Gore, 2018a; Embrett, Randall, Longo, Nguyen, & Mulvale, 2016; Hart & Maslow, 2018; Mulvale et al., 2015; Muñoz-Solomando et al., 2010; Nguyen et al., 2017; Paul, Street, Wheeler, & Singh, 2015) scanned to reveal classic or seminal works integral to this topic’s conceptual development. This strategy exposed an additional seven studies, which were then subjected to the same screening and reduction process as records accumulated through database searching.

Articles were initially excluded if the full-text version could not be accessed, an English translation was unavailable, publication had not taken place within the past ten years (between 2010 and 2019), or if the study was conducted outside of Canada, the United States, western Europe, or Australia, given the assumed structural dissimilarities with the Canadian healthcare system. The titles and abstracts of the remaining 357 articles were then reviewed to determine relevancy to the TAY demographic and mental health or social service contexts, as well as the transferability of study findings and implications for the enclosed research. Finally, full-text articles were assessed for eligibility based upon the aforementioned criteria, resulting in a modest

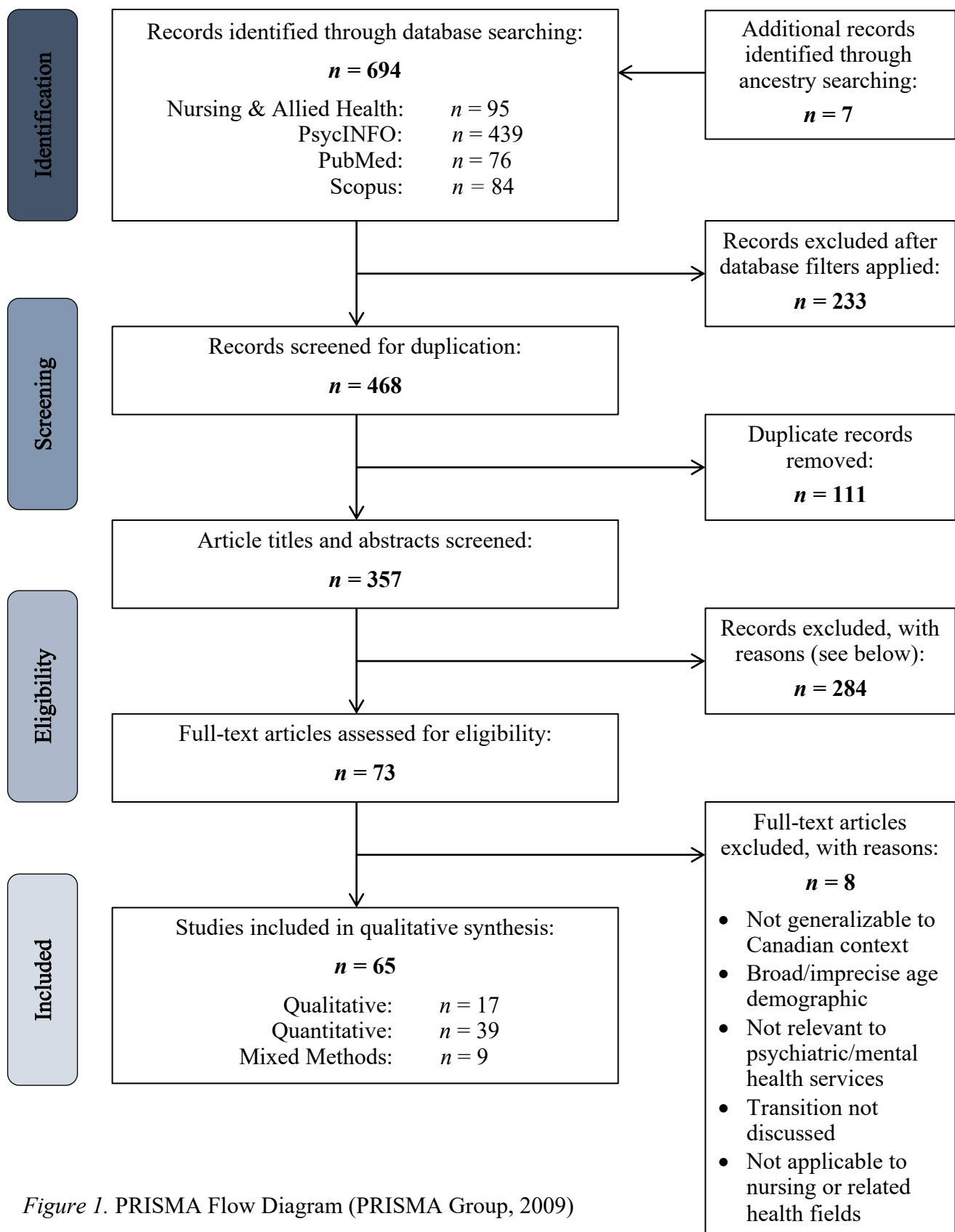


Figure 1. PRISMA Flow Diagram (PRISMA Group, 2009)

65 studies included in qualitative synthesis. Refer to Figure 1 for a graphic depiction of this step-wise process. The narrative review of accumulated TAY mental health literature that follows, provides a broad summary of current trends and common themes that transcend research disciplines, ontological perspectives, and methodological frameworks. General characteristics of included studies are represented in Table 1 below.

*Table 1.* Literature Review Sample Characteristics

Characteristic	<i>n</i>	%
<u>Year of Publication</u>		
2019	2	3.1
2018	7	10.8
2017	14	21.5
2016	10	15.4
2015	5	7.7
2014	5	7.7
2013	5	7.7
2012	4	6.2
2011	4	6.2
2010	2	3.1
2009 or earlier	7	1.5
<u>Country/Region</u>		
United States	27	41.5
Canada	22	33.8
United Kingdom	10	15.4
Scandinavia	4	6.2
Australia	2	3.1
<u>Methods</u>		
Qualitative	17	26.2
Quantitative	39	60.0
Mixed Methods	9	13.8

## Youth Dissatisfaction

Of the 17 qualitative studies reviewed, 15 adopted an interpretive lens, utilizing



descriptive methods, such as case studies, focus groups, and semi-structured interviews to explore the lived experiences of youth transitioning to adulthood (Broad et al., 2017). Findings from such analyses reveals that frustration with the mental health system often leads to untimely withdrawal from necessary psychiatric supports (Murcott, 2014; Pottick, Bilder, Stoep, Warner, & Alvarez, 2008; Singh et al., 2010). This already-turbulent period of change corresponding with various developmental milestones and role transformations (MacLeod & Brownlie, 2014), is further complicated by the abrupt shift to adult psychiatric services. Patient narratives across studies echo a resounding sense of distrust and abandonment during this time of institutional flux and instability (Burnham, Preyde, & Porto, 2015; Munson, Scott, Smalling, Kim, & Floersch, 2011; Murcott, 2014). Young people consistently voice concern regarding the loss of established clinical relationships and therapeutic interventions (Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014), and report feeling unknowledgeable and ill-equipped to navigate this transition independently (Jivanjee, & Kruzich, 2011).

While such perspectives were espoused by the majority of youth studied, select analyses highlighted the unique challenges faced by young people with additional vulnerabilities, such as: TAY with a concurrent developmental disorder or medical comorbidity; those engaging in problematic substance use; ethnic minorities; individuals identifying as LGBTQ+; impoverished youth or those without a fixed address; adolescents transitioning out of foster care; and incarcerated youth facing imprisonment at an adult detention facility or forensic mental health centre (Fowler, Toro, & Miles, 2011; Hart & Maslow, 2018; MacLeod & Brownlie, 2014; Kalinyak, Gary, Killion, & Suresky, 2016b; Manuel et al., 2018; Munson, Lee, Miller, Cole, & Nedelcu, 2013; Munson et al., 2011; Osgood, Foster, & Courtney, 2010; Piel & Lacasse, 2017). Owing to the intersection of their non-traditional identities and lifestyles, TAY belonging to one or more of these categories are marginalized by compounding oppressive forces. As such,

intensified stigma and structural violence significantly reduce the accessibility, efficacy, and safety of psychiatric services for these individuals (MacLeod & Brownlie, 2014).

A number of qualitative and mixed-methods studies supplemented TAY experiences with the insights of caregivers and clinicians, thereby triangulating the scope of this issue through a diversity of perspectives (Henderson et al., 2017; Hovish et al., 2012; Jivanjee & Kruzich, 2011; Lindgren et al., 2014; Livesey & Rostain, 2017; Manuel et al., 2018; Miller, Sukhera, Lynch, & Wardrop, 2017; Munõz-Solomando, Townley, & Williams, 2010; Por et al., 2004; Singh et al., 2010; Stein et al., 2016; Tobon et al., 2015). Emerging adult concerns were echoed by personal and professional allies, who — despite advocating for significant improvement in TAY psychiatric service delivery — felt powerless to influence such change because of structural barriers, including financial constraints, restrictive organizational policies, or broader societal considerations (Miller et al., 2017; Stein et al., 2016). Many also experienced additional stress related to system navigation, as institutional inefficacies and ambiguities among TAY mental health services meant family members, friends, and trusted healthcare providers were often looked to for compensatory guidance and support (Tobon et al., 2015).

### **Disparate Systems**

While many similar themes emerged from the descriptive qualitative approaches utilized across studies, researchers and healthcare providers must not become complacent. Rather, an acute awareness of the heterogenous nature of mental health experiences among emerging adults, reveals a profound need for individualized care (Mental Health Commission of Canada [MHCC], 2015). This period of transition is marked by unprecedented levels of patient disengagement with psychiatric services (Pottick et al., 2008), which is believed to be influenced by the stark contrast between paediatric and adult mental health care philosophies and treatment models (LaPorte, Haber, & Malloy, 2016). Commentary on this juxtaposition by Mulvale et al. (2015)

provides a detailed description of the nurturing and family-centered care practices emphasized by child and adolescent psychiatric services, varying considerably from impersonal adult services that prioritize autonomy and confidentiality. Often-stunted psychosocial maturation exacerbated by paediatric-onset mental health challenges further complicates this progression; thereby contributing to a reticence or delayed maturity that thwarts TAYs efforts to autonomously navigate the adult mental health system (Davis, 2003). Abrupt psychiatric care divisions arbitrarily defined by chronological age, rather than developmental stage, force TAY to suddenly assume total responsibility for their mental health care, when many lack the requisite knowledge, self-efficacy, and decision-making capacity to independently engage in treatment planning and implementation (Kaufman, Horricks, & Kaufman, 2010). Such a dramatic culture shift can be improved by offering flexible approaches that are tailored to individual needs (Davis, Koroloff, Sabella, & Sarkis, 2018). Hovish et al. (2012) advocate for early and sustained youth involvement throughout the transition process — from initial care planning to reflective exercises post-changeover — to encourage patient empowerment and self-determination across the care continuum (Gilmer, Ojeda, Fawley-King, Larson, & Garcia, 2012; LaPorte et al., 2016). Brownlie, Chaim, Heffernan, Herzog, and Henderson (2017) discuss the importance of youth engagement in research related to TAY psychiatric program development, in order to inform needs-based service design, revitalization, and implementation.

### **Proposed Solutions**

A significant proportion ( $n = 39$ ) of the literature relied upon quantitative data collection and analysis methods to enumerate the scope and severity of psychiatric service gaps impacting the TAY population (Lindgren, Söderberg, & Skär, 2013; Martel, & Fuchs, 2017). Through evaluation of process and outcome indicators (Cappelli et al., 2016; Cleverley, Bennett, & Jeffs, 2016; Singh et al., 2017), researchers agree upon several challenges and opportunities for

advancement (Park, Adams, & Irwin, 2011; Rushton, 2011). Emerging adults require an integrated, accessible, and highly responsive mental health system that spans health promotion, crisis intervention, psychiatric assessment, treatment, and community reintegration services across inpatient and tertiary care settings (MHCC, 2015). By incorporating the perspectives of all relevant stakeholders in the development and implementation of evidenced-informed psychiatric programs, healthcare service providers may establish collaborative partnerships that build capacity among youth transitioning to adulthood (Evidence Exchange Network for Mental Health and Addictions, 2016; Gray, Monaghan, Marchak, Driscoll, & Hilliard, 2015; Sukhera et al., 2015).

“[Changing] the mindset from *aging out* to *continuing on*” — a statement by Manuel et al. (2018, p. 263) — succinctly conveys the need for a paradigmatic shift that prioritizes continued psychiatric intervention, rehabilitation, and recovery beyond the confines of paediatric care. In order to establish robust developmentally-appropriate supports, McGorry, Bates, and Birchwood (2013) advocate for policy change to facilitate the centralization of government responsibility for mental health care, in order to amalgamate and reallocate funds and resources based upon need rather than jurisdiction. Cleverley et al. (2018b) encourage the strategic migration of TAY-oriented psychiatric services from acute hospital environments to community facilities that are more responsive to the immediate, practical, and everyday needs of emerging adults. This relocation would also facilitate opportunities for more proactive, upstream mental health approaches that enhance the strength and resiliency of TAY facing circumstantial stressors (Sukhera, Lynch, Wardrop, & Miller, 2017). Finally, a variety of the reviewed studies incorporated evidence-based recommendations into the design and implementation of progressive TAY psychiatric service models, which attempt to bridge the mental health care chasm formed by incongruent paediatric and adult systems (Jabbour et al., 2016; Kalinyak, Gary,

Killion, & Suresky, 2017; Munson et al., 2017; Ojeda et al., 2016; Ousch et al., 2019; Rickwood et al., 2019). Critical learnings reported by TAY mental health research teams across jurisdictions inform the continued modification and refinement of adaptive, integrated care systems that more effectively meet the psychosocial care needs of the emerging adult population (Settipani, Cleverley, Hawke, Rice, & Henderson, 2017; Sukhera et al., 2015)

### **Gap**

Despite the large volume of available evidence that validates the need for political action and policy revision, only one article reviewed utilized critical qualitative research methods to expose injustices and advocate for emancipatory change (Sukhera et al., 2017). While many studies identify gaps in the provision of transitional care (Lindgren, et al. 2013), the perspectives of young people are consistently underrepresented in conversations regarding youth-oriented psychiatric program development (Youth Select Committee of the British Youth Council, 2015), despite a clear desire to share their personal narratives (Munõz-Solomando et al., 2010). Furthermore, the nursing viewpoint was noticeably absent from the literature, with only seven of the referenced studies published by scholarly nursing peer-reviewed journals (Fegran et al., 2014; Kalinyak et al., 2016a; Kalinyak et al., 2016b; McGrandles & McMahon, 2012; Moynihan et al., 2015; Murcott, 2014; Por et al., 2004). Through the intersection of clinical, research, educational, consultative, leadership, and advocacy roles, nurses are ideally-suited to build upon existing evidence by supporting and empowering TAY engagement in participatory approaches to transformative action and meaning-making.

### **Purpose**

The research study outlined in this manuscript — titled *The PhotoSTREAM* (Supporting Transition-Readiness for Emerging Adults with Mental health challenges) *Project* — sought to address the aforementioned knowledge void within nursing and interprofessional health

literature, by exploring the perspectives of TAY living with mental health challenges, who have progressed from paediatric to adult psychiatric services. Through a combination of photography, interviews, and focus groups, the Photovoice method (Wang & Burris, 1997) was employed to illuminate youth interactions with the mental health system during this period of transition. Insights gathered using this collaborative, participatory, and action-oriented research framework not only highlight the strengths and shortcomings of existing policies and practices that impact quality and continuity of care for this demographic, but also reveal participants' collective vision for optimal mental health care across the transitional period. Findings from the PhotoSTREAM Project (henceforth referred to as *PhotoSTREAM*) contribute to an enhanced awareness of psychiatric service delivery gaps experienced by emerging adults, and advocate for seamless and supportive transitions that more effectively meet the mental health care needs of the TAY population. Furthermore, implications derived from emergent themes elucidate opportunities for nurse involvement in the enactment of disruptive solutions to manage this issue. All study procedures were guided by, and maintained accordance with, the research question: *How do youth with mental health challenges experience the transition from paediatric to adult psychiatric services?*

## **Method**

### **Theoretical Grounding**

Aligned with the sociopolitical mandate of nursing science, which seeks to address systemic health inequities, this work draws upon the tenets of Critical Social Theory (CST) to expose mental healthcare-related injustices experienced by emerging adults, and to encourage responsive action through youth engagement (Browne, 2000). Integral to this humanistic philosophical perspective are the principles of social responsibility and community building (Duchscher, 2000). By challenging oppressive forces, CST promotes the agency and

empowerment of marginalized populations constrained by harmful legislation and policy (Creswell & Creswell, 2018). CST epistemology purports that knowledge is socially-constructed; thereby rejecting the positivist belief in universal truth (Fontana, 2004). As such, nursing inquiry embedded within the critical paradigm embraces the idiosyncratic and reflexive nature of qualitative research. CST conceptualizes truth as fluid and inherently subjective, contending that information devoid of personal meaning invalidates wisdom acquired through lived experience (Campbell & Bunting, 1991).

## **Design**

Emerging from CST, participatory research endorses the transformation of traditional empirical processes as an antecedent to enhanced clinical practice (Burns & Grove, 2005). Using collaborative and action-oriented approaches, liberal investigative ideologies support radical participant-driven change — the impact of which is manifested both broadly and deeply (Richards & Morse, 2013). Drawing upon such ontological perspectives, PhotoSTREAM was conducted using a youth-led participatory action research (YPAR) framework in order to engage study participants throughout the entirety of the research process (Ozer, 2016). Regarded by the nurse-researcher as experts on the phenomena of interest, TAY were actively involved during design and implementation phases, as well as the conception of knowledge dissemination initiatives following thematic analysis (Nykiforuk, Vallianatos, & Nieuwendyk, 2011). This process was cyclical in nature, requiring continuous reflection and action from all stakeholders to inform future research and practice that will address the unique challenges faced by the TAY population (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009). By exposing institutional barriers to psychiatric service utilization during the transitional period, participants had the opportunity to serve as mental health advocates and change-agents.

Considered a modernization of critical ethnography (Sutton-Brown, 2014), the

Photovoice method was employed to unearth the subjective realities of PhotoSTREAM participants. Traditionally used to generate public awareness and interest in issues pertaining to marginalized communities, Photovoice brings stifled and concealed experiences to the forefront of societal consciousness, in order to effect meaningful sociopolitical reform (Catalani & Minkler, 2010). Originally conceptualized as a health promotion tool by Wang and Burris (1997), Photovoice combines photography and experiential learning with critical reflection, discourse, and analysis. Such techniques promote participant empowerment, community ownership, and social justice by adhering to three overarching goals: (a) conferring autonomy upon participants through ongoing involvement and influence in research processes; (b) identifying, synthesizing, and translating knowledge regarding the values, strengths, and challenges faced by a particular vulnerable population; and (c) reaching policymakers and political leaders through language and photographs that are both accessible and impactful (Wang & Burris, 1997). Such theoretical underpinnings closely align with the objectives of this study, making this progressive qualitative method ideally-suited to elucidate and advocate for the unique needs of youth living with mental health challenges as they transition to adulthood.

### **Sample and Setting**

PhotoSTREAM targeted emerging adults with self-identified mental health challenges, who accessed psychiatric services during childhood and/or adolescence. This description encompasses both acute inpatient psychiatric supports, as well as outpatient ambulatory care, and may have been related to crisis intervention, assessment, treatment, or rehabilitation. A formal diagnosis based upon criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> Edition (APA, 2013) was not required for participation, as mental health status is fluid and may necessitate intervention, irrespective of a formal diagnosis. While PhotoSTREAM sought to explore a spectrum of transition experiences, an enhanced understanding of the



progression from paediatric to adult services required that participants' mental health challenges must have endured since turning 18, to the extent that they may have benefitted from professional psychiatric supports. This criterion was not only necessary to determine whether TAY continue to access such services upon entering adulthood, but also whether the support received adequately meets their mental health care needs.

Recruitment catered to TAY currently residing in the city of London or surrounding rural municipalities of Middlesex County; however, participants may have received mental health care anywhere within the province of Ontario. Given that London serves as a temporary place of residence for many students pursuing post-secondary education, an assumption was made that eligible participants may have relocated from another region. That being said, policies governing mental health in Canada are enacted largely at the provincial/territorial level and can therefore differ greatly across such jurisdictions. Restricting wide-ranging psychiatric services to a defined geographic location, provided consistency when exploring participants' transition experiences, while also embracing slight variations in healthcare provision by institution and practitioner.

**Eligibility.** Interested TAY were required to meet the following eligibility criteria for participation in PhotoSTREAM:

1. Able to read, write, and converse fluently in English
2. Between the ages of 18 and 24 at the time of study commencement
3. Received paediatric mental health care within the province of Ontario prior to reaching the age of majority
4. Experienced mental health challenges since turning 18 that necessitated professional psychiatric support, but which may or may not have been acquired
5. Access to a digital camera, smart phone, or portable electronic device with

photographic functions, and ability to upload images to a secure OneDrive folder, through wireless internet connection, USB cable, SD card, or other means

6. Agree to audio-recording of focus group dialogue

**Recruitment.** Using a purposive sampling strategy, study participants were recruited via poster advertisements (Appendix A) placed throughout London, Ontario at community support services frequented by those with mental health challenges, as well as social hubs that are popular among the TAY demographic, such as public parks, recreation facilities, community centres, libraries, coffee shops, and movie theatres. Additionally, recruitment posters were featured at post-secondary institutions, namely Western University, Fanshawe College, and several private career colleges throughout the city. Public presentations at community events, as well as local television (Moreau, 2019) and print media interviews (Callahan, 2019) generated additional excitement among potential participants. TAY, mental health service providers, and allies also were also given the opportunity to request print or electronic copies of recruitment materials to share among their personal or professional networks via social media or traditional means.

All advertisements included a link to the PhotoSTREAM website ([www.photostreamproject.org](http://www.photostreamproject.org)) with information about the study, as well as an email address through which interested parties could voluntarily contact the research team to express their intent to participate. Subsequently, candidates received a response listing inclusion criteria and logistical details surrounding study involvement. At this initial time of contact, an electronic copy of the study's Letter of Information (LOI) (Appendix B) was provided, and eligible participants had the opportunity to ask questions and express any concerns before giving informal consent to participate. Those who remained interested received an orientation guide (Appendix C) via email, providing a brief overview of all study-related procedures, self-care

strategies, and some basic education regarding photography best practices. Formal written consent was collected at the first in-person encounter, at which time each participant received a paper copy of the LOI (Appendix B) to retain for their records. A total of eight TAY ( $n = 8$ ) were selected to participate in PhotoSTREAM, guided by the abovementioned recruitment process. This sample size was sufficient to achieve data saturation, and is consistent with the established methodological precedent outlined in Photovoice literature (Catalani & Minkler, 2010; Evans-Agnew, Boutain, & Rosemberg, 2017; Lal, Jarus, & Suto, 2012).

### **Data Collection**

Participants were involved in this project for approximately one month, during which they were invited to take part in three weekly 90-minute focus group sessions (Appendix D). At the beginning of the first session, TAY engaged in icebreaker activities, established a set of shared group expectations and community norms, and were asked to sign a confidentiality agreement (Appendix E) — promising to respect the privacy of their peers by: (1) not disclosing or transmitting personal information discussed during focus groups to anyone outside of the research team; and (2) not referring to themselves or fellow participants by full name or other personal identifier while dialogue was being audio-recorded. Participants then completed a brief anonymous questionnaire (Appendix F), capturing general demographic characteristics, and information regarding their interactions with the mental health system across paediatric and adult care realms. Such data was used to broadly describe participants involved in this study, and is presented in tables 2 and 3 of this chapter's *Findings* section. Given PhotoSTREAM's qualitative research design, outcomes are not generalizable to the larger population of interest; rather, demographic information gleaned through this questionnaire serves to contextualize participants' photographs and responses to guided questions.

In preparation for the first focus group session — and each session thereafter —

participants were asked to take photographs that reflected a specific topic related to their personal mental health care experiences throughout the transitional period, using their own digital camera, smart phone, or other electronic device. Listed sequentially, weekly topics included: (a) *the good* — positive experiences during the transition from paediatric to adult psychiatric services; (b) *the bad* — negative experiences during the transition from paediatric to adult psychiatric services; and (c) *the vision* — a vision of optimal mental health care during the transition from paediatric to adult psychiatric services. Since it can be difficult to articulate complex experiences through words alone, this guided photography process afforded participants the creative freedom to visually portray personal knowledge and meaning, and thus served as the foundation for focus group discussions (Cabassa et al., 2012; Woodgate, Zurba, & Tennent, 2017; Wang, & Burris, 1997).

Participants were invited to identify one to two photographs, which they felt best reflected the weekly topic, to be printed for use at the upcoming focus group session. Each session involved individual reflection and collaborative discussions about participants' images, as well as sorting, titling, and captioning activities that aided in the discovery of overarching themes and patterns. Participants were given time to write freely about their selected photograph(s) during each focus group session, responding to the six questions outlined in the *SHOWED* method developed by Wallerstein and Bernstein (1988): (a) what do we *See*?; (b) what is really *Happening*?; (c) how does this relate to *Our* lives?; (d) *Why* does this issue exist?; (e) how can we become more *Empowered* by understanding this issue?; and (f) what can we *Do* to address this issue? TAY were then invited to share their unique insights with the group; thereby stimulating valuable collaborative discussion that informed the titling and captioning of each photograph. Following group dialogue, participants summarized the concepts and themes that emerged throughout the session, and briefly discussed the next week's topic. At the end of the

final focus group session, TAY were invited to complete a brief, anonymous program evaluation questionnaire (Appendix G) to provide constructive feedback about their involvement in PhotoSTREAM, including the feasibility, acceptability, and effectiveness of the Photovoice method to address the posed research question.

TAY also had the opportunity to take part in an optional 30-minute semi-structured interview (Appendix H), should they have wished to share any insights or perspectives outside of the peer group environment. One-to-one conversations with the four ( $n = 4$ ) participants who requested such an interview contributed to a richer understanding of their personal mental healthcare journey, and helped to illuminate the unique systemic barriers and strengths that influenced their psychosocial wellbeing during the transitional period. Photographs captured by each participant and printed for use during earlier focus group sessions were present at the interview, offering an opportunity to provide additional clarification about their thought-processes and artistic decisions.

### **Data Analysis**

Thematic analysis of participants' experiences with the mental health system during the transitional period was conducted using a descriptive qualitative approach that combined pile-sorting techniques (Bernard, 2002) with Strauss and Corbin's (1998) constant comparative method, in order to develop an integrated coding structure that accounts for both visual and narrative data. Following collaborative photo-elicitation discussion during each focus group session, participants codified their own printed photographs and corresponding written elements, by assigning titles and elaborative captions. TAY then categorized images into mutually-agreed upon piles that best reflected the thoughts and feelings evoked upon observation, when reading the attached title and caption, and by recalling pertinent group dialogue. While this approach was non-prescriptive in nature, participants were asked to adhere to three basic criteria when

pile-sorting: (a) all photographs could not be assigned to a single pile; (b) all photographs could not be assigned to their own separate piles; and (c) each photograph could only be assigned to one pile. Upon completion, participants applied a descriptive label to each pile produced, which accurately represented all photographs belonging to a particular set.

Analysis of audio-recorded focus group dialogue and participants' written reflections were augmented using NVivo 12 data management software (QSR International, 2018). Resulting codes, along with a list of all photograph titles, captions, and pile labels were presented to the group for discussion and approval during the subsequent focus group session. Participants and researchers were given equal opportunity to accept, reject, or modify codes identified with appropriate rationale. Following the final focus group session, participants were invited to take part in an optional data analysis meeting to collectively cluster codes into categories and ascertain overarching themes (Strauss & Corbin, 1998). While many participants demonstrated interest in the data analysis process, TAY requested that an executive summary of study findings (Appendix I) be sent to all participants following the completion of the project, in place of an in-person meeting. This decision largely stemmed from conflicting employment, academic, and vacation schedules, as well as relocation outside of the London area for the summer season. Participants preferred the convenience and flexibility associated with written correspondence. TAY will be kept informed of all future research activities resulting from their participation in PhotoSTREAM, and their input obtained during focus group discussion will be directly integrated into post-study knowledge dissemination activities.

### **Knowledge Dissemination**

Consistent with the Photovoice approach, principles of empowerment, collaboration, and social justice will be thoughtfully incorporated into all knowledge translation activities, while also maintaining the utmost respect for privacy, confidentiality, and anonymity. It is anticipated

that research findings will be published in scholarly peer-reviewed journals and presented at academic conferences; however, non-traditional methods will also be employed to grant participants agency in this process. TAY input obtained through focus group discussions will be integrated into the development of knowledge dissemination activities. While specific post-study knowledge translation activities have not been conceptualized at this time, TAY have expressed interest in the creation of an awareness program, to extend knowledge beyond the confines of academia, and to allow for the transferability of findings across contexts and locations. Ideas discussed to date include a youth-managed public gallery showing, online photography blog, and postcard print media campaign. Such projects would serve to engage policymakers, political leaders, community influencers, and local media organizations in thoughtful reflection and discourse surrounding participant photographs, and associated PhotoSTREAM findings.

### **Rigour and Authenticity**

While YPAR is deeply embedded within the critical paradigm (Ozer, 2016), efforts to explore and understand the lived experience of the TAY demographic prior to engagement in social justice and emancipatory initiatives, required an interpretivist lens. This perspective acknowledges the collaborative, intersected, and reciprocal nature of exchanges between researchers and participants, in which derived meaning is shared (Guba & Lincoln, 1994). Within the context of YPAR, and specifically Photovoice, TAY participating in this study were considered co-creators of evidence (Catalani & Minkler, 2010). The pre-existing knowledge, experiences, values, and beliefs of all parties should therefore be acknowledged as having guided the nature and trajectory of interactions during focus group sessions and individual interviews. Consequently, the facilitator consistently endeavoured to practice from a perspective of sincerity, transparency, and self-reflexivity, in order to prevent any undue influence that may silence the

voices of an already-vulnerable population. Participants were viewed as ambassadors for the TAY community and maintained active involvement throughout all stages of the PhotoSTREAM research process (Ohmer et al., 2013). While it is argued that transactional validity cannot be fully achieved in the qualitative realm (Cho & Trent, 2006), every attempt was made to uphold participatory methodological fidelity.

In an effort to ensure trustworthiness and rigour, an audit trail was generated, encompassing meeting minutes, analytical memoranda, and correspondence, in order to account for the inherent fluidity and evolution of the study purpose (Cho & Trent, 2006). Transactional validity was further enhanced through the triangulation of data sources, collection strategies, and theoretical positionality, in order to construct a more robust and accurate picture of this community's reality (Guba & Lincoln, 1994). Finally, methods were consistent with the collaborative underpinnings of YPAR, and incorporated regular member-checking activities to ensure mutual agreement upon emerging themes, joint interpretation and validation of findings, and involvement in the brainstorming of knowledge dissemination initiatives. In keeping with this participatory approach, field notes were not used as a source of data collection, as external observations and subjective interpretations may have influenced the coding and subsequent themes generated. Accordingly, such precautions prevented an inequitable distribution of power between the researcher and participants.

### **Ethical Considerations**

Authorization for PhotoSTREAM was obtained through delegated review by the Health Sciences Research Ethics Board (HSREB) of Western University, the regulatory body which governed the ethical conduct of this project. An approval letter for protocol 2019-112971-21550 was received from the HSREB on February 19, 2019 (Appendix J). The study was carried out in accordance with the four widely-accepted principles of healthcare ethics espoused by



Beauchamp and Childress (2012) — autonomy, beneficence, non-maleficence, and justice — thereby ensuring the human rights of participants were consistently prioritized over research objectives. Unique to the Photovoice method, however, are a complex interplay of actors, techniques, and motivations that necessitate the acknowledgement of additional ethical concerns beyond this standard principled approach. Wang, Morrel-Samuels, Hutchison, Bell and Pestronk (2004) developed a comprehensive set of considerations to assist fellow critical qualitative researchers in mitigating the ethical risks inherent in the Photovoice process, such as photographing others without their knowledge or permission, exposing the identity of an individual or community, portraying subjects in a negative light, or misrepresenting a situation. Wang et al. (2004) advocate for education and collaborative discussion regarding the intersection of photography and procedural ethics, particularly surrounding the issue of informed consent. For this reason, PhotoSTREAM participants were provided with a highly-detailed orientation guide (Appendix C) that clearly described all study-related procedures in greater depth than was outlined in the initial LOI (Appendix B).

TAY were strongly encouraged to refrain from photographing specific people or organizations involved in their mental health care. Rather, participants were coached to *think outside of the box*, by showcasing phenomena and utilizing artistic effects that elicited emotions, thoughts, or perspectives consistent with those experienced during their transition. Nonetheless, participants were provided with written consent forms (Appendix K) and instructed to obtain express permission from any individual whose face, body, or belongings they chose to photograph. In the case of identifiable property, personnel, or facilities attributable to a particular organization, TAY were taught to seek consent from someone in a senior leadership position, such as a manager, director, or coordinator, who had the authority to grant such permissions. Photographs of anything generic or unrecognizable did not require written consent.

TAY received a weekly check-in via phone or email to ensure ongoing safety and engagement in the Photovoice process, to offer guidance and support as needed, to troubleshoot any issues that may have arisen, and to remind them of the upcoming meeting time and location.

Given PhotoSTREAM's many components, consistent efforts were made to minimize participant burden. Electronic copies of all study documents were supplied in order to maximize convenience and accessibility of information. Focus groups were hosted in private meeting rooms at the London Public Library — a centrally-located setting supportive of grassroots-level community initiatives, and easily accessible via public transit. For each focus group attended, refreshments were provided to all participants as a thank you for their involvement in the research process. Participation in all study-related procedures was entirely voluntary — as such, TAY were not disadvantaged or excluded from PhotoSTREAM if they were unable to attend all sessions. Furthermore, weekly photography assignments were completed independently and according to each person's unique availability. Mindful of participants' busy schedules and competing priorities, additional data collection tools including the demographic questionnaire and program evaluation survey were made optional and integrated into time allotted for focus group sessions. Individual interviews were also not required, and were only offered to enhance the comfort and confidentiality of the participants who may have preferred to disclose certain information without their peers present. Several participants vocalized that personal benefits related to social interaction and creative processes significantly outweighed the demands of study involvement.

While the risk of heightened emotional sensitivity related to study participation was expected to be minimal, the raw and unedited visual depiction of participants' lived experience carries the inherent potential for re-traumatization. Walsh, Hewson, Shier, and Morales (2008) endorse a balanced approach to photography, encouraging participants to capture both positive

and negative perspectives of their reality to guard against such risks. Accordingly, divergent weekly topics endorsed a well-rounded reflection of TAYs transition experiences, while also guarding against undue bias and influence by the researcher. Participants were explicitly cautioned regarding the disclosure of personal mental health challenges, and focus group discussions were therefore centred around interactions with paediatric and adult psychiatric services. TAY were also invited to take breaks during focus group sessions and interviews as needed, and encouraged to engage in health-promoting selfcare practices to support their psychological and physical wellbeing. Participants were led through guided mindfulness activities, and fidget toys were made available to TAY who wished to engage in meaningful distraction exercises during times of individual reflection and group discussion. In the unlikely event that participants were to experience emotional distress at any point throughout the duration of the study, they were urged to contact appropriate local mental health and crisis services — a comprehensive list of which was provided as a handout at the first focus group session (Appendix L).

Photovoice researchers should give due consideration to moral issues that may extend beyond data collection and analysis phases, such as the portrayal of vulnerable persons within academic and sociopolitical spheres during knowledge dissemination initiatives (Wilson, Kenny, & Dickson-Swift, 2017). Throughout the YPAR process, it is imperative that investigators strictly adhere to principles of relational ethics, remaining mindful of their position of privilege, and continually demonstrating respect for participant agency through collaborative efforts (Tracy, 2010). As described in *Data Analysis* and *Knowledge Dissemination* subsections respectively, TAY will receive an executive summary of study findings, and input obtained during focus group discussions will be actively integrated into future publications, presentations, and awareness projects. Pseudonyms have been used to communicate the perspectives of

individual participants in the upcoming *Findings* section, and any personal identifying information has been redacted. While no distinguishable persons, locations, or property were depicted in any images, participants were asked to sign a photograph release form (Appendix M), granting permission for their work to be used for print and/or multimedia publishing by Western University for knowledge dissemination purposes. All written study information was anonymized and securely stored in locked University research offices, while electronic data was saved to cloud storage behind the institutional Firewall. Focus group discussions and individual interviews were captured on a portable audio-recording device without access to the internet. Audio files were uploaded to secure institutional cloud storage before being saved to an encrypted USB drive for ongoing analysis purposes. Original audio files were promptly deleted from the recording device and were never listened to in public spaces.

Banks et al (2013) encourage the establishment of robust safety protocols when engaging in such sociopolitically-driven, and therefore emotionally-charged, research. These measures not only support the continued psychosocial health and empowerment of participants, but also prevent ostracization, exploitation, and the perpetuation of stigma directed toward the population in focus. Additional challenges arise when engaging vulnerable and/or marginalized groups in YPAR, including those experiencing mental health challenges. Depending upon the degree to which their condition impacts daily functioning, these individuals may have difficulty appreciating the demands of study participation (Gillon, 1994; Ramcharan & Cutcliffe, 2001). As such, TAY who expressed interest in PhotoSTREAM were granted several opportunities to ask questions and seek further clarification regarding study-related procedures prior to providing formal written consent to participate. Electronic and paper copies of the LOI were shared and thoroughly reviewed with each participant to ensure comprehension and full appreciation of the associated risks and benefits.

## Findings

Study findings were generated through a variety of data sources, namely: demographic information gleaned from written questionnaires; participant photographs and associated titles, captions, and written reflections; as well as dialogue recorded during focus group discussions and individual interviews. In order to contextualize emergent themes, general characteristics of TAY involved in this study are described in the *Participants* subsection below, including a brief overview of their interactions with the mental health system.

### Participants

PhotoSTREAM garnered a total of eight ( $n = 8$ ) participants, each of whom maintained varying degrees of involvement throughout the duration of the study, due to its flexible design and voluntary nature. It should be noted, however, that 14 TAY met eligibility requirements and were invited to participate following their initial expression of interest. While reasons for disengagement or withdrawal were not always made explicit, several emerging adults cited their mental health challenges as a contributing factor. Demographic characteristics of study participants were acquired from a ten-item questionnaire. Owing to the study's small sample size ( $n = 8$ ), response frequencies and percentages have not been reported, so as to protect the identity of TAY involved.

Ranging in age from 19 to 23 years, all TAY enrolled in PhotoSTREAM were born in Canada, with a majority of participants self-identifying as Caucasian, women, single, and of heterosexual orientation. Educational attainment varied; however, most participants indicated that they had completed either a secondary school diploma or university degree, and half of participants reported having secured full- or part-time employment. While most TAY did not align with a particular faith, there was diversity among religious beliefs, including Christianity and Judaism. Results also demonstrated considerable socio-economic variability, with self-

estimated annual household incomes ranging from \$20 000 to over \$100 000. Please refer to Appendix F for a full list of questions posed, and corresponding response options.

A second questionnaire captured participants' paediatric and adult mental health experiences. Responses presented in Table 2 demonstrate considerable variability across participants. Having received a combination of child/adolescent and adult psychiatric services, most TAY ( $n = 6$ ) rated their transition as either negative or very negative, and their current mental health status as only fair ( $n = 3$ ) or poor ( $n = 4$ ). Three quarters ( $n = 6$ ) of those surveyed believed appropriate services were available, but not accessible — citing financial cost ( $n = 7$ ) and wait times ( $n = 6$ ) as the most significant barriers to access. While one participant specified that the non-inclusive nature of psychiatric supports also served as an important obstacle, a majority ( $n = 6$ ) of TAY felt that their mental health care providers were respectful of the personal identities they hold. Favourably, 88.5% ( $n = 7$ ) of participants reported feeling actively included in care decisions, with varying levels of involvement by allies such as family members, caregivers, or close friends. TAY were invited to describe Ontario's mental health care system in one to three words. A word cloud illustrating participants' selections are illustrated in Figure 2. A weighted representation, the term *inaccessible* is larger than all other words, as it was used by two different participants. All other phrases appeared only once across surveys. Of the 21 words provided by TAY, all but one are blatantly negative. The term *potential* is the only response that suggests hope and the possibility of improvement.

Table 2. Mental Health Experiences

Characteristic	<i>n</i>	%
<u>Child/Adolescent Services Received</u>		
Crisis Services	4	50.0
Inpatient Psychiatric Services	3	37.5
Outpatient Psychiatric Services	8	100.0
Other: Residential Treatment Services	1	12.5
<u>Adult Services Received</u>		
Crisis Services	5	62.5
Inpatient Psychiatric Services	3	37.5
Outpatient Psychiatric Services	7	88.5
<u>Transition Experience</u>		
Very Positive	0	0.0
Positive	2	25.0
Neutral	0	0.0
Negative	5	62.5
Very Negative	1	12.5
<u>Current Mental/Emotional Health</u>		
Excellent	0	0.0
Very Good	0	0.0
Good	1	12.5
Fair	3	37.5
Poor	4	50.0
<u>Availability/Accessibility of Services</u>		
Available and Accessible	1	12.5
Available, but not Accessible	6	75.0
Not Available	0	0.0
Unknown	1	12.5
<u>Barriers to Access</u>		
Competing Priorities	4	50.0
Cost	7	88.5
Service Hours	3	37.5
Stigma	0	0.0
Transportation	4	50.0
Wait Times	6	75.0
Other: Non-Inclusive Services	1	12.5

Table 2. Mental Health Experiences, Continued

Characteristic	<i>n</i>	%
<u>Respectful Mental Healthcare Providers</u>		
Strongly Agree	4	50.0
Agree	2	25.0
Neither Agree nor Disagree	1	12.5
Disagree	1	12.5
Strongly Disagree	0	0.0
<u>TAY Involved in Care Decisions</u>		
Strongly Agree	2	25.0
Agree	5	62.5
Neither Agree nor Disagree	1	12.5
Disagree	0	0.0
Strongly Disagree	0	0.0
<u>Inclusion of Family, Caregivers, and/or Friends</u>		
Always	1	12.5
Usually	2	25.0
Sometimes	2	25.0
Rarely	3	37.5
Never	0	0.0



Figure 2. Word Cloud



## Emergent Themes

Given the qualitative design of this study, findings will not be used to generalize the thoughts, opinions, and beliefs of all TAY receiving mental health care across the province; rather, emergent themes will help to illuminate positive and negative transition experiences shared by study participants, regardless of the specific services received or the setting in which mental health care took place. Below are the insights and patterns that materialized through participatory data analysis.

**Photography.** The photographs selected by TAY to guide focus group discussions are categorized below by weekly topic — (a) *the good*; (b) *the bad*; and, (c) *the vision*. Photographs are further subclassified according to the set of images formed through the use of Bernard's (2002) collaborative pile-sorting technique outlined in the earlier *Data Analysis* section of this chapter. The descriptive label assigned to each resultant set serves as the subheading under which photographs are presented. Participant-selected titles and captions accompany all images, along with brief narrative descriptions of the photographs' subjective meaning and significance, derived from TAYs written reflections and verbal exposition during the *gallery walk* portion of focus group sessions. While each image was captured by a single photographer, its implications were determined through iterative group discourse and analysis. Decisions regarding all themes were made collaboratively, and photographic narratives should therefore be considered a product of the PhotoSTREAM collective. Due to the reciprocal and fragmented nature of these discussions, direct quotations are not used to substantiate the image descriptions found below. Rather, such can be found in the *Dialogue* subsection that follows, which details the unique thoughts and ideas vocalized by participants through various photo-elicitation activities.

**The good.** This initial topic pertained to participants' positive experiences during the transition from paediatric to adult psychiatric services. While at first glance, the images appear highly diverse, three central themes were identified by TAY as transcending multiple photographs.

**Fresh beginnings.** The images belonging to this set represent a dramatic shift in perspective. While all participants alluded to the challenges associated with their transition process, each were able to derive meaning from such complexities and perceive positive outcomes that manifested accordingly. Figure 3 explores a phenomenon in which hazy treatment objectives are brought into focus upon entering adulthood. The handheld design of the mirror was a deliberate artistic choice by the photographer, signifying enhanced agency, influence, and maturity associated with *aging out* of paediatric mental health services. A clearer sense of direction, largely attributable to greater involvement in one's own care, restores the horizon to an image of hope and beauty, rather than confusion and darkness.

Figure 4 features a desk affixed to a classroom chair, in an open, accessible, and inviting position. Arranged such that it is able to accommodate someone new, this seat at the proverbial table symbolizes the navigation away from family-based treatment, and toward freedom and independence. While still intact, the transition process influences the relationship between TAY and caregivers, such that youth are afforded greater decision-making capacity and authority; thereby,



**Figure 3. Clarity.** A new perspective, a clearer vision — in your hands.



**Figure 4. Sitting on Opportunity.** You don't have to be closed off in treatment.

enhancing the comfort associated with adult psychiatric services.

The apple trees featured in Figure 5 are *ripe with possibility*. The increased opportunities concomitant with adult mental health care — including more precise diagnoses, widely available psychiatric medications, and greater variation among therapeutic interventions — provide emerging adults with exposure to new choices. This expanded scope of treatment options yields a more comprehensive, robust foundation, leaving TAY feeling grounded. Such support is a welcome *breath of fresh air* that nurtures personal growth and encourages an openness to ever-changing circumstances.

*Hope*. This second set of photographs encapsulates the endurance of optimism and future orientation in spite of adversity. Participants felt the word *HOPE* was particularly appropriate for this theme, given its acronym for *Hold On, Pain Ends* — a widely-used mantra within mental health circles. Figure 6 depicts the pathway to adult psychiatric services. Situated within a dark and secluded area, the path appears daunting and isolated, with its final destination hidden from sight. Prescriptive and inflexible treatment protocols often leave TAY feeling trapped and powerless to change directions when warranted. Past experiences along one's mental health care journey can be utilized to inform future therapeutic decisions, like vines woven among the archway overhead. Such learnings may help TAY to *chart their own course*, trusting that while the road



**Figure 5. Growing Options.** With age comes more opportunities, more choices, and more ‘roots’ for treatment, services, and pharmaceutical aids.



**Figure 6. Moving Forward Along a Path.** The knowledge we have is represented in the vines on the metal arch, and we can use that to better our paths into the future.

to recovery may be hazy and somewhat foreboding, everyone walks along a unique path, and at their own pace.

Figure 7 reveals the importance of allyship and guidance within provider-patient dyads. When confronted with a loss of supportive professionals and services, many TAY feel *in the dark* regarding their mental health care. Untethered and uninformed, emerging adults lose sight of their treatment goals and often withdraw from adult psychiatric programming. Through recognition of one's intrinsic power, however, TAY may use self-advocacy as a tool to illuminate their mental health challenges. Furthermore, proactive help-seeking behaviours allow healthcare providers to respond by *shining a guiding light* that brightens and clarifies the transition process. Through validation and egalitarian approaches, such positive therapeutic relationships may spark improved treatment engagement among emerging adults; thereby, reigniting a once-extinguished flame.

Though perhaps not obvious at first glance, Figure 8 represents the prioritization of self-care during periods of heightened stress and vulnerability accompanying the transition to adult mental health care. Using cooking as a means to engage the senses, nourish the body, and express creativity, one participant discussed how their relationship with food served to mitigate anxiety, while enhancing passion, productivity, and personal achievement.

*The end.* The final set of images pertaining to the first weekly topic represented the culmination of adolescence, and its associated psychiatric services. Figure 9 depicts a cityscape



**Figure 7. Illumination.**  
In dark times there is  
always light.



**Figure 8. Taco.** Shows  
growth, the passage of  
time, and that you can  
take inspiration from  
anywhere.

at dusk. The darkness, mystery, and silence often associated with twilight are indicative of the distress, confusion, and apprehension experienced by many emerging adults as they *age out* of paediatric mental health care. While such circumstances can be challenging, like nighttime hours, they are transient, and will eventually pass. At dawn, the sun begins to rise and TAY are exposed to new adult-oriented psychiatric resources and supports.

Figure 10 is a photograph of Christmas pudding. A thoughtful amalgamation of simple ingredients, this dish represents one's ability to make meaning from seemingly negative or insignificant occurrences. During the transitional period, emerging adults bring with them tremendous strength and wisdom garnered through their paediatric mental health care experiences. This image also demonstrates the sociological and cultural significance of food. A treasured family recipe that has been passed down through several generations, this pudding is representative of tradition, legacy, and celebration. A unifying force, food serves to strengthen relationships and enhance personal comfort — characteristics that are sought by many TAY transitioning to adulthood.

Finally, Figure 11 features a closed blue door, and is illustrative of the pivotal moment when TAY must say goodbye to paediatric mental health services. While this abrupt shift is undeniably difficult, participants considered it to be integral to their personal development, feeling as if they had outgrown many of the supports to which they had become accustomed.



**Figure 9. End of an Era.** When the sun sets at the end of the day and childhood treatment comes to an end, it still holds hope that the sun will naturally rise the next day, and adulthood treatment will begin.



**Figure 10. Pudding.** It represents history, family, and the times.



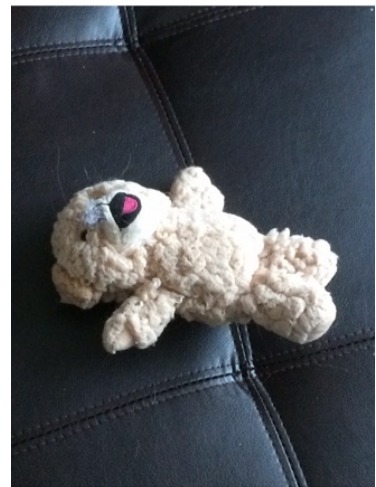
Reflective of the colloquialism *when one door closes, another opens*, this door also demonstrates new possibilities, and the decision-making capacity of emerging adults who may not only choose whether to proceed forward, but also how they go about doing so. Hesitancy to accept such new opportunities can be thought of knocking on a stranger's door before entering. By cultivating a welcoming and supportive environment, or by extending an open invitation, healthcare professionals can help to ease the anxieties of TAY choosing to take this daunting first step.



**Figure 11. Open Door.**  
When one door closes,  
you are the key to a  
new one.

**The bad.** Selecting images for the second weekly topic was described by participants as being significantly less challenging. All considered their transition process to be primarily negative, despite acknowledgment of specific positive elements.

**Bare.** This first theme is centered around the concept of vulnerability. While the specific trajectory endured by each participant was vastly dissimilar, many spoke of moments during the transitional period when they felt invalidated, unsupported, and helpless. Figure 12 is an image of a stuffed bear that serves as a dog's chew toy. With its stitching torn and padding exposed, this bear has been *chewed up and spit out* — akin to TAYs experience of mistreatment, neglect, and/or abandonment by mental health services.



**Figure 12. Bear.**  
Chewed up, spit out,  
beat up, and put through  
the wringer.

Similarly, Figure 13 depicts a barren, withered, and decaying tree planted in isolation from other vegetation. Indicating distress and suffering, this evocative photograph sparked a critical discussion about hopelessness and suicidal ideation, during which participants spoke of a

desire for sustained psychological support following one's departure from paediatric care, as well as more proactive and tailored crisis assessment and intervention strategies.

The fallen Buddha sculpture featured in Figure 14 is permanently damaged, yet remains largely intact. Representative of emotional instability and inadequate support systems, this ceramic artifact ultimately fell to the ground because it was resting upon a foundation with poor structural integrity. TAY described feeling *unsteady* and *broken* at various points throughout their transition, unable to rely upon the professionals and services entrusted with their psychiatric care. Despite superficial cracks, the sculpture did not shatter and has maintained its original form, just as many participants have persisted despite enduring incredible hardship.

*Cracks.* While the visual similarities between the images assigned to this set are uncanny, each photograph is nuanced in its portrayal of insecurity, distance, and incongruence. Figure 15 showcases the convergence of four distinct cracks in the pavement, forming one large fracture. These lines epitomize the various weaknesses of TAY mental health care, and the many possible ways in which young people may inadvertently *fall through the cracks*. Participants discussed the importance of integrating youth perspectives and feedback into the appraisal of existing transition pathways, as well as the visioning of new and innovative treatment protocols.

A crosswalk signifying the disjointed progression from adolescent to adult services is



*Figure 13. Tree.*  
Dead — not wanting to be here.



*Figure 14. Cracked Open.* Broken and unfixable — no steady ground.

depicted in Figure 16. Crossing from one side of the street to another is a potentially dangerous task in which pedestrians are vulnerable to oncoming traffic. Navigating a busy intersection without robust safety measures such as traffic lights or crossing guards increases the level of risk associated with this activity. Participants suspected that TAY who are adequately supported by targeted transition services or personnel may experience better mental health compared to those who must transverse this chasm alone.

Figure 17 features a crack in the road, thereby merging the subject matter of the previous two photographs. This large fissure represents the mental health service delivery gaps between paediatric and adult care realms, resulting from a lack of transition planning and follow-up. Confusion related to the competing priorities of these disparate systems stems from a lack of guidance, causing TAY to feel unsupported and isolated, and eventually fade into the background. Withdrawal from necessary psychiatric treatments and interventions may ultimately increase the likelihood of adverse health outcomes, placing youth in a precarious position.

*Choiceless.* The remaining two photographs illustrating negative transition experiences demonstrate confusion and a perceived loss of autonomy. Figure 18 shows a package of granulated sugar next to a synthetic sweetener. This juxtaposition is intended to differentiate *the real* from *the artificial* when assessing the merits of opposing psychiatric treatment modalities. While equally sweet, high-calorie sugar represents the consideration of deeply-entrenched



**Figure 15. Cracks in the Sidewalk.** Four cracks emerge.



**Figure 16. The Gaps.** There lies a gap between adolescent and adult treatment.



systemic issues contributing to poor psychosocial wellbeing, while the more marketable sweetener is consistent with symptomatic, *one-size-fits-all* interventions. The latter may require less time and energy to be expended, however, its implementation does not address the root cause of psychosocial dysfunction. Using disordered eating behaviours as an example, one participant discussed how their treatment was reactionary in nature, focusing predominantly upon food selection and eating habits, rather than the underlying mental health challenges contributing to the development of such unhealthy lifestyle choices. Therapeutic measures that do not maintain alignment with individual needs leave TAY feeling as if they have little control over their mind and body.

Lastly, Figure 19 is a photograph of someone carrying shopping bags. This image can be interpreted quite literally, as it symbolizes the need to *shop around* for accessible and effective mental health services. This process can be both tiresome and expensive, requiring TAY to search blindly for resources without the requisite education or guidance regarding available treatment options. Transition support beginning in paediatric care may help to mitigate the stress and financial burden associated with independent system navigation upon entry into adulthood.

**The vision.** The final weekly topic tasked participants with capturing phenomena representative of optimal mental health care across the transitional period. Resulting images



**Figure 17. Fallen.** Exposed to the world with no protection.



**Figure 18. Artificial Sweetness.** A choice between sweet and real, and sweet and artificial.

generated lively discussion with several innovative solutions posed.

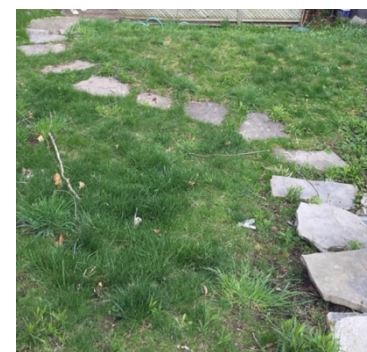
*Stepping stones.* Three photographs were categorized under this theme, which broadly illustrates the gradual and step-wise nature of ideal transition processes. Depicting a winding stone path, Figure 20 represents the progression from paediatric to adult psychiatric services. While its curvature indicates the inherent variability of the transitional period, clearly demarcated segments demonstrate the need for distinct therapeutic stages, beginning the moment youth first interact with the mental health system. Although the end of the path is hidden from view, upcoming milestones are plainly visible; thereby supporting well-defined treatment goals and objectives. Ebbing and flowing in response to individual needs, the integration of choice along this path enhances autonomy, extending power and control to TAY whose mental health challenges may already limit their personal freedoms.

Figure 21 showcases an extensive album collection, in which CDs are catalogued by artist or band. Representative of role clarity and collaboration among all parties engaged in the transition process, each album has a designated position, and is called upon in response to ever-changing needs. TAY require *harmonious* involvement among all stakeholders, including active participation and transparent communication in order to support smoother and stronger care transitions.

The puzzle pieces featured in Figure 22 are a *work in progress*. Collectively forming a



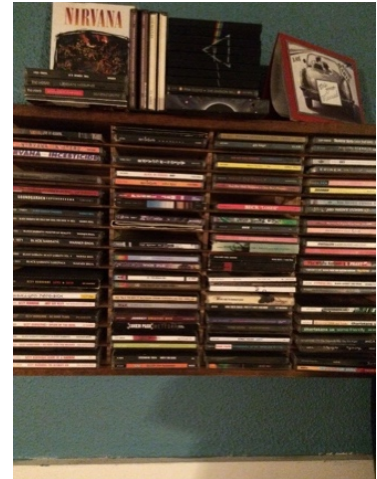
*Figure 19. Shopping Around.* The burden of carrying around a bag of emotions while seeking the right fit for care.



*Figure 20. Set in Stone Path.* Having a guiding path makes the long walk easier.

single image, the assembly of these pieces symbolizes the many people and agencies that must effectively collaborate to support TAY with mental health challenges. Each stakeholder is regarded as an invaluable component of the transition process, just as all pieces must be present in order to complete a puzzle. While pieces are incongruent and may not always *fit together* perfectly, client-centred care philosophies should ultimately guide the direction of treatment, ensuring that the psychiatric needs of emerging adults are prioritized above the ideas or perspectives of individual health professionals, caregivers, or allies.

*Clarity.* Images assigned to this set represent the simplicity, transparency, and precision desired by TAY throughout the transitional period. Figure 23 depicts a night stand built by one of the participants. Requiring considerable patience and close attention to detail, this structure is not only visually appealing, but also highly functional — capable of supporting several items within its storage compartments. A direct comparison can be drawn when considering the organized and pragmatic approach required during transition processes. Guided by a clear set of expectations or *blueprints*, early planning with TAY should govern all future treatment decisions. Just as wood has its inherent flaws, stakeholders should consistently endeavour to allay unexpected challenges, ensuring a *smooth exterior* and *natural finish* that instills confidence among emerging adults without concealing minor imperfections. Furthermore, efficacious and robust intervention strategies mirror the structural soundness of the pictured object, offering a



**Figure 21. Albums.** My Dad's CD collection that started in the 90s and continues to grow.



**Figure 22. Pieces.** Piecing together the transition process.

supportive foundation upon which TAY can consistently rely.

Clear blue skies can be seen through the window photographed in Figure 24. Optimal psychiatric care for TAY would feature similar lucidity, conducive to direct two-way communication between emerging adults and healthcare professionals. While closed at present, this window has the capacity to open, representing barrier-free access to mental health services.

Figure 25 features a sea salt lamp. Uniquely formed, no two salt lamps are alike in appearance, just as mental health treatment approaches should be tailored to each individual. Actively releasing heat and repelling negative ions from the surrounding environment, such objects have natural cleansing and purification properties. Similarly, psychiatric interventions are designed to address negative thoughts, feelings, and behaviours; thereby creating space for personal growth and development. Effective treatment for TAY strikes an appropriate balance between confronting mental health challenges, and celebrating one's efforts and successes.

*Light at the end of the tunnel.* This final theme suggests that positive transition experiences can be achieved through creativity and flexibility. The rainbow hot/cold compress pictured in Figure 26 demonstrates the need for versatility and customization across mental health interventions. Generalized, impersonal treatment programs do not account for individual differences in psychiatric rehabilitation and recovery. As such, healthcare providers should



*Figure 23. Little Desk.*  
A night table built in woodshop.



*Figure 24. Breath of Fresh Air.* Opening the windows of opportunity.



continuously adapt their clinical approaches — exhibiting warmth and compassion when possible, while also setting firm professional boundaries and clear expectations consistent with *tough love*. The rainbow is also representative of the light that emerges following a storm. Through the enhancement of self-efficacy and resilience, TAY should be supported by health professionals to learn effective coping strategies that instill hope during the darkest of times.

Finally, Figure 27 features a fence that serves as a physical barrier, impeding direct access to the river in the background of the image. While it is certainly not impossible to circumvent this obstacle, the fence may slow one's progress. While there will always be challenges that TAY must face during the transition process, it is possible to effectively *bridge the gap* between paediatric and adult psychiatric services, facilitating the safe passage from one side of the river to the other. When executed thoughtfully, and at the pace of each individual, emerging adults may experience enhanced growth and development, as reflected by the blossoming trees and flowing stream. Somewhat concealed in this image, the overpass in the distance is representative of the tendency to dismiss pre-existing resources and supports when engaging in problem-solving activities. Through ongoing consultation with TAY during all stages of transition planning and program implementation, first-hand experiences may be used to strengthen existing knowledge of mental health service delivery gaps, and advocate for innovative and disruptive solutions.



**Figure 25. Crystal Clear.**  
Release negativity,  
find clarity.



**Figure 26. Find a Rainbow.** There is hope  
at the end of the storm.

**Dialogue.** Audio-recordings of focus group sessions and individual interviews were reviewed and analyzed by the researcher to identify recurring topics of conversation, as well as statements that reached a general consensus among participants. These were subsequently shared with TAY, who had the opportunity to accept or reject findings based upon relevance and significance. Participant selections were then clustered into the four overarching themes outlined below. Descriptions are supported by direct quotations, which serve to contextualize and clarify the intended meaning of each theme. In a concerted effort to



*Figure 27. Bridging the Gap.* Crossing the bridge from adolescent to adult services.

protect the identity of all participants, TAY have been assigned pseudonyms, and any information implicating specific persons or organizations has been redacted. Each of the narratives featured represent individual experiences, and should therefore not be generalized to reflect the opinions or perspectives of all TAY with mental health challenges.

**Accessibility.** Conversations regarding the limited availability of desired mental health services, as well as systemic barriers hindering access to those offered, quickly emerged as a common grievance among participants. While referred to adult psychiatric services by a Paediatrician prior to graduating from high school, Riley described a significant delay before such services were actually received. During this time span, Riley was forced to wait patiently without any mental health support, despite severe chronic anxiety:

I remember it was at least a few months before I actually got to [see] the Psychiatrist, and then [...] it had to have been in total at least a year from the initial conversation with my Family Doctor to actually starting the group therapy and [...] hospital [programs].

Jordan expressed a similarly challenging gap in the provision of mental health services, after being discharged from an acute inpatient psychiatric treatment program for adolescents. Due to

the added complexity of rurality, however, Jordan's geographic location significantly limited access to outpatient resources upon entering adulthood:

I had to wait over a year for my Psychiatrist after being hospitalized and everything. [...] There were accessibility issues because [...] I was located in St. Thomas as opposed to London. If I was located in London I would have been able to access a Psychiatrist after I was hospitalized [...] but because that wasn't the case, I had to wait.

The time-limited nature of many adult psychiatric programs only exacerbated such frustrations. When discussing situations that made TAY feel particularly vulnerable or alone, Maria shared her experience being repeatedly denied sustained psychiatric treatment after turning 18:

I think for me it was not having access — so, like when I did go to my Family Doctor and was like “I want to have an adult Psychiatrist”, she was like “honestly, there's no such thing”. She's like “it's not possible”. [...] They don't see people long-term — it's like the only specialty I can think of that doesn't see anyone long-term. [...] I kind of had that experience when I went to [a psychiatric hospital in Toronto]. It's a great program because they like go from ages 16 to 25, except that everything there is eight weeks. [...] I loved it there, so I was like “can I stay?”, and [my Family Doctor] was like “honestly, no”. [...] And same with the counselling — like that ended as well. Like, it's an eight week — more of a crisis — [program], getting you back on track. That was in Toronto, and then I came back to London, like about a month later [...] and I reached out to the [satellite] location here, and I was like “I'm interested in continuing services here”, and they asked me if I was a [post-secondary] student. So when I said “yeah”, they said they “don't provide services to students because they're only for the people in the community”. And then the waitlist at [school] is like three months to see anyone, so that's where I kind of felt like I was hanging dry [...] because like literally I couldn't see anyone no matter what I tried. It was impossible.

Many participants echoed this sense of abandonment, feeling as though it had contributed to their overall distrust in the mental health system. A lack of consistency among care providers and convoluted intake processes meant that TAY were required to repeatedly disclose highly sensitive personal information — a routine described as *triggering*, *emotionally exhausting*, and even *numbing*. Having retold their *story* upwards of 15 times throughout the course of their psychiatric treatment, participants were understandably frustrated. Kayla and Ellie summarized the problematic nature of this standard procedure, and its resulting negative impact:

Kayla: When you're seeing a new professional you have to tell like your whole life story again and again, which can be like really hard and slightly traumatic because you don't want to go through everything.

Ellie: [...] With the new Psychiatrist I had to be like reassessed, and it was just an hour and a half of her asking me a lot of questions and me having to like be very open and honest with someone I had just met. [...] And then [...] she didn't respond in the way that I was needing and hoping — because some of the stuff was very fresh, or stuff that I hadn't talked about in a while. [...] I didn't end up going back to see that Psychiatrist, just because it was really exhausting and kind of traumatizing [...] and I didn't get the empathy I was hoping for.

The fear of such re-traumatization alone was enough to prevent some participants from seeking ongoing psychiatric support, or to withdraw from services already acquired. Conversely, a rote memorization of, and consequent desensitization to one's story often contributed to feelings of fatigue and self-doubt — barriers that made James hesitant to continue asking for help:

I think I've become like apathetic to my own experience. I have this problem where I tend to like heavily intellectualize my emotions, so already that's a barrier to accessing care [...] because like sometimes it's like they're not even there. It's just words on a page. [...] And that feels very disempowering because it's almost like it's something that hasn't even happened to me — it's just something that I say. And the emotional impact of the words lose their effect because it's like just a regular thing. And I find that [...] it makes me feel like the experience is not as bad as I initially perceived it to be [...] When you talk about it in that tone it doesn't seem like anything is going wrong. And so like maybe people who are on the mental health support side will lose their sense of urgency in the situation because [...] the emotionality of things just doesn't translate.

Several participants spoke about the extraordinary monetary cost associated with private adult psychiatric services. For those with insurance coverage obtained through school, their parents/guardians, or employer, there were often stipulations regarding the type, frequency, and duration of treatment, and many agencies required proof of a formal psychiatric diagnosis. Left with more questions than answers, Riley shared the confusion experienced when navigating the bureaucratic complexities of this process:

[...] Now it's that matter of — okay, how do I find someone that's covered? Or, how much do I get covered from my parents' plans? Or maybe I should just wait until I get my own coverage through a job?

During their transition from paediatric to adult mental health care, many TAY described being



*let down* by the publicly-funded system due to excessive wait times, limited resources, or unhelpful healthcare providers. Jordan acknowledged the financial burden associated with enjoying the benefits of private mental health care:

Personally, I don't feel that publicly there is anything in addition to medication, so I have to [...] pay for private [psychotherapy]. [...] With private [services] they actually go out of their way to help you [...] and they're more [focused] on pleasing you. [...]. I feel like I've gotten better services [...] and more availability. [...] Their hours are definitely more flexible. [...]. But it sucks because [private services] are very unaffordable for most people. Personally, if I'm accepted to the program at [a private residential treatment facility], I'm going to have to use money out of my education savings, that my family put away for me, in order to pay for the program.

Also left with no alternative but to access private services, Ellie disclosed how significant monetary concerns exacerbated existing mental health challenges:

I fell through the cracks with support that was covered, so I looked to private supports — and that ended up being really helpful — but that comes at a cost, and I don't want to like burden my mom and my family with all of that, so I pay for my therapist. [...] Her prices just increased today, so it's just kind of an emotional day, just because like I'm mad that there's like another barrier, and that like I might not be able to see her anymore, just because it's like hard with the financial strain — being in school and not being able to work. I'm moving out [of the family home], so I'll like have to pay for rent and everything too.

Another common barrier for participants was the exclusivity of services, particularly for TAY with non-normative identities, beliefs, or lifestyles. Many participants alluded to a lack of education and awareness among mental health professionals, which sometimes resulted in dismissive, intolerant, or prejudicial comments and behaviours. As a queer person, James identified several unique challenges that impacted the accessibility of psychiatric treatment:

[...] That aspect of my identity has a huge impact on my experience. [...] I would also say that it has an impact on the way my anxiety manifests. There are more things that I think about — more kinds of specific worries that I have, that are more quote/unquote “real”. Like, for example, experiencing violence is not out of the question, and it's something that has happened before. So, in that sense, I kind of have to be careful who I talk to — or at least I feel like I have to be careful who I talk to — and that poses a bit of an accessibility barrier in terms of like how open I'll actually be about my experience and how much of the story they'll get. Like, if I leave out the queer identity part [...] if I just talk about my experience of anxiety, [I'm] only talking about, let's say, 80% of [my story], but that extra 20% is not being actively addressed half of the time. [...] There is

this weird thing where you feel like you're constantly having to like *come out* to people, so you don't want that to be an additional process in your counselling experience — specifically in like crisis counselling where they don't have a lot of time — so to like deconstruct your own identity in front of them, that would be a lot to unpack.

For nearly all participants, concerns related to accessibility were identified as the most negative aspect of their transition experience. In one case, however, personal barriers to mental health care were described as having significantly decreased upon reaching the age of majority. Alex stated the following when asked about the differences between paediatric and adult psychiatric services:

I think accessibility is the big thing. Like I'm literally just able to talk to someone, they refer me, and boom — I'm there within a couple of weeks. And like I'm able to choose who I want to go see. [...] Whereas like as a kid, I really wasn't able to. If I got through the door of a therapist's office, then it was just like "you get this person". I never got to choose.

While the system is far from perfect, this last quotation highlights the potential for TAY to feel adequately supported and cared for during their search for mental health services. If many of the above-mentioned barriers to access are addressed, perhaps similar success stories will become more commonplace.

**Coordination.** In addition to accessibility barriers described above, a lack of communication and information-sharing — both with TAY and between health professionals — significantly impeded continuity of care for those progressing to adult services. Such disharmony was further exacerbated when therapeutic interventions required the cooperation of multiple organizations. Left without any mental health resources in the interim, Riley discussed the *gap* in care delivery that was experienced following referral to new psychiatric supports:

I was mostly just waiting, and I wasn't really sure what the process was going to entail. [...] There were a lot of these pieces — and it was like they were there, but nothing was flowing or going together. It wasn't actually helping as well as it could have if everyone was talking to each other and the patient.

Poorly-coordinated care was a particular concern for participants that relocated to a new region

— a common occurrence for many TAY who choose to pursue post-secondary education in another city. Unable to acquire an adult Psychiatrist during her first year in London, Maria was forced to return to Toronto to access such support:

I switched cities, so it's hard for like one city to refer to another. [...] At the end of the summer before leaving for [post-secondary school], [my care team] basically said “good luck”. [...] When I tried to access services in London, I was told there was a six month wait [...] so when I wanted to try medications I knew I had to go back home, because I didn't have the option here to see someone quickly. And that's when I went to [a psychiatric hospital] in Toronto. They have an Emergency Department just for mental health [...] and through there you get a one-time appointment with a Psychiatrist who then refers you to one of their clinics. [...] So then when it was time to return to [post-secondary school] they were like “there's not much we can do” — and they kind of let me go — “and we don't know any [of the services] in London, so we can't suggest anything”, and “if you want to come back, you have to go through the Emergency Department process all over again”. So that sucked! [...] I was out of resources again.

Disjointed transitions and absent follow-up procedures once again resulted in many participants *falling through the cracks*. Ellie discussed the demand for wraparound transition support extending beyond an initial referral:

[My paediatric Psychiatrist and mental health nurse] kind of did the referral [for adult services] — like they filled out the forms — but there wasn't any follow-up with how my first appointment went. And then since it did not go well, I fell through the cracks there — like I didn't have [paediatric supports] to fall back on. They also didn't involve my new therapist into it, which would have been helpful since she just came on when I was just about to turn 18. And I think incorporating any of those supports that I had would have been helpful, just so I could have felt better supported instead of dropped all of a sudden. [...] Just because they filled out the paperwork, doesn't mean their job was done.

Maria advocated for assertive, proactive communication by referring clinicians — whether through a conference call or in-person meeting — to ensure clear messaging regarding TAY psychiatric needs and treatment goals. Believing that TAY should also be present during such conversations, open dialogue would enhance continuity, while minimizing opportunities for the misinterpretation or omission of information:

I think it's about the connecting of services that you shouldn't have to do on your own. I think it's your [care provider] [...] knowing you're going to [post-secondary school], reaching out to [the local psychiatry program] and saying, “I have a patient — she needs

this type of counselling and this is how often I see her — what can you do?”

By *connecting the dots*, participants may have felt more adequately supported throughout the transition process. Instead, many reported feeling *ignored, abandoned, or neglected* during this period of already-heightened vulnerability. In fact, several TAY disclosed that necessary referrals were only made after the severity of their condition had escalated to the degree that they had experienced an acute crisis episode. For Jordan, community supports were not solidified until an involuntary admission to the hospital:

I would have been screwed to be honest. [...]. Had I not been hospitalized [...] it wouldn't have been good for me. I would have ended up not having a provider at all.

Overwhelmingly, participants craved clarity and transparency from their healthcare providers regarding the nuances of the transition process. Unsure of what to expect from adult psychiatric services, and how these changes might align with existing treatment goals, Ellie, Kayla, and Mitch recounted how their concerns were repeatedly dismissed, minimized, or avoided entirely:

Ellie: I think I was just like ill-prepared for what was to come. And like speaking about transitioning and adult services — those conversations were never really had. They were just sort of put on the back burner, or just completely avoided until it was too late. [...] Or they just leave you hanging and say like “oh, we'll talk about it in a bit, but not right now”. [...] [Having these conversations] is really important and they just down-play it and don't see how serious it is. And then finally they're like “well, here are your options — okay, got to go, bye”.

Kayla: Mine didn't happen at all. There was no conversation. [...] As I was getting closer and closer [to age 18], appointments were made farther and farther away, until like there was just one day where I don't think I made a next appointment, and I never went back.

Mitch: I kind of felt like I had just been dropped. [...] Like when I turned 18 I knew it was coming, so I asked them about it, and they were like “don't worry, we're not going to just drop you — we're going to wait until you get better and we're going to help you”. And then I just continued to just go to my regular appointments, and the one day I got there, and they were like “okay, by the way, this is your very last appointment and you have to leave after today”. And I was like, “excuse me? What?” I was really mad, I was angry.

Ellie: I wish people were just straight up about how it was going to be. I think that would have really helped me to be more hopeful in overcoming those barriers.

Without adequate guidance or preparation, many participants did not have a concrete sense of direction. Uninformed of available services, Maria was unsure where to begin her search for viable psychiatric supports:

It's not that there's a lack of resources, it's just that they're *so* hard to access and there's no one telling you where these services are.

Having to self-advocate for appropriate treatment, most participants felt unsupported in their pursuit of adult mental health care. James discussed how societal pressures that accompany the transitional period can exacerbate the stress of newly-acquired adult care responsibilities:

Because you're pretty much entirely responsible for yourself — which is like a huge part of growing up — [...] it can be absolutely exhausting to access help, because you're not only booking your own appointments, following up on emails, going to different services, identifying those services, telling your story — which can be emotionally exhausting — you're doing that alongside all of your academic, extracurricular, and social obligations. [...] It can become a very frustrating process in and of itself, but then it becomes even more frustrating in the sea of other things you have to do.

Riley desired the extension of adolescent services well beyond the age of 18, owing to the chaotic and tumultuous nature of emerging adulthood:

As soon as you turn 18 you're not all of a sudden how you would be at like 45. [...] The adolescent services I got were very helpful, but it was [assumed] when I turned 18 that I all of a sudden didn't need that same sort of care. I still would have benefitted greatly — no, I would *still* benefit greatly, if I had continued to go to that same Psychologist. [...] Obviously I've grown up a lot since then, but I'm still in a similar mindset [...] and I know you need to have some sort of cut-off, but [...] is there a way to support [TAY] through university or during a stage that doesn't mean you're having to transition when everything else is falling apart at the same time?

Many participants felt that their discharge from paediatric services was premature and abrupt. Furthermore, TAY generally believed they lacked the emotional readiness and maturity necessary to even secure appropriate adult mental health supports, let alone benefit from such services. Suddenly required to take full responsibility for his mental health care, Mitch disclosed feeling overwhelmed and ill-equipped to navigate this transition independently:

When I finally got to see a Psychologist that dealt with adults [...] I talked to him for like an hour, and then he handed me three brochures, and that was it. [...] Going and looking for help on your own is like terrifying to me and I felt like in child care they didn't really give me the skills I need to navigate it on my own. And they kind of just expected me to figure it out. [...] You're expected to become an adult overnight after you turn 18, but I still felt like me — nothing's changed, I'm still me. [...] And I didn't go to a lot of things when I was a teenager because I was so anxious about everything. I missed out on so much, I felt like my teenage years were taken from me, so I was like "I'm not ready to be an adult yet, I've barely been a teenager".

Echoing this sentiment, Alex described the conflicting expectations of adolescence and adulthood that undermine transition success:

Almost overnight it was expected that I had to do everything for myself. But up until I turned 18 I was spoon-fed, and I wasn't really allowed to make decisions for myself. And then I turned 18, and they're like "alright, well you need to know how to do this, and this, and this".

***Independence.*** Building upon the statements above, participants experienced a dramatic increase in their ability to exercise personal autonomy following their 18<sup>th</sup> birthday.

Appreciative of newly-acquired respect, James discussed the ageist attitudes of health professionals that were frequently encountered as an adolescent:

I think before you're 18 years old, your opinions are like just instantaneously less valid than someone who is older. And that's obviously a function of ageism, but no matter your knowledge level or your confidence level, people perceive you as a kid, and therefore they kind of treat you as a kid. Which is like fine when you're younger I think — it gives you some guiding principles to move forward effectively — but as you get older and you're trying to assert yourself in the world, it kind of feels a little less empowering, and it feels more like you're being guided to say certain things or act in a certain way. [...] In my three years with my [paediatric] Psychologist, I don't think I ever felt that I could be fully honest, because I always felt like there was this distance between us.

Such doubt and invalidation resonated with many participants, who felt that their opinions were seldom considered when accessing paediatric services. This led to a chronic distrust in mental health care providers, and a stifled expression of one's thoughts and emotions. Alex succinctly described how arrogant and patronizing comments contributed to a growing sense of inferiority:

It's the condescending attitudes: "I'm older, and therefore I know more". There's a real power differential there.

Unfortunately, several participants found that such discrediting behaviour extended into adult care, and that concerns were more appropriately attended to when a parent or advocate was present. Maria shared her experiences as a patient and an ally — in both instances, TAY mental health symptoms were dismissed and overlooked until another person expressed concern:

The difference for me is that when a parent is there [...] showing concern, you're taken more seriously. [...] If you were to come in on your own, they'd be like "oh, it's her again", but if there are other people there who are genuinely concerned, they treat you differently. [...] I'm also a support person for a lot of friends, and I always feel like without me [health professionals] would have doubted them too. So when I come with them to the Emergency Department, the doctor looks at me and he's like "what do you think?". And I'm not even a parent! [...] They ask me my opinion on the treatment, and I'm just a support system with no blood relation — an equal to the patient — and they'll turn to me first and say, "what has [the patient] told you?" [...] Now that I've been in both positions, and I see that, I would never go to the hospital by myself.

By calling TAYs decision-making capacity into question and favouring the perspectives of a family member or friend, health professionals significantly undermine the authority of individuals with mental health challenges. Several participants were able to recall similar circumstances where they felt completely ignored; often because their care provider had engaged a parent or guardian in a private conversation, as if they were not present or capable of contributing to the discussion. Such a blatant disregard for personal autonomy was described as *disempowering* and deeply *upsetting*.

An added complexity that impeded TAYs efforts to exercise independence, was the pervasive fear of breached confidentiality. In the paediatric system, care providers often demonstrated a loyalty to parents/guardians — prioritizing their desire for inclusion over a child's right to privacy. Regularly overhearing the disclosure of personal information, Alex became increasingly distrustful of health professionals:

I would hear [my paediatric Psychologist] talking to my Mom after the session, and like telling her stuff that we had talked about. And I'm thinking, "well I'm sitting right here, and I can hear you — 1) I can hear you making fun of me, and 2) I didn't tell you that you could tell her". It was like she took my Mom's side on everything. [...] Then when

[my Mom and I] went to the Pharmacy to pick up my medications, the Pharmacist turned to her and started telling her everything. And I'm like, "okay, I'm old enough to know how to properly take medicine, so you should tell *me*". [...] It's very invalidating — the system. It's like "oh, well you're a kid, you don't know anything". "You say this, but you don't actually mean it".

Similarly wary, James became more guarded — strategically withholding information from care providers after trust was broken:

I know that my mother contacted my [paediatric] Psychologist semi-regularly, and so I didn't know how much I could trust my Psychologist with the information that I was giving her. And so that kind of made my experience feel less empowering than it should have been, I'm sure.

Such concerns were particularly relevant for participants with strained parental relationships. In contrast to the paediatric system, adult mental health care afforded TAY the opportunity to engage with services independently; thereby, avoiding unwanted parental control. Kayla discussed how an increased influence over care decisions resulted in a concurrent sense of freedom and relief:

I could start advocating for myself [...] and seeing the help that I knew I needed, or like looking into other things that I wouldn't want to tell my parents about. [...] I can go access the programs and kind of keep [my parents] at a distance, and give them what I want them to know.

Post-transition, many participants felt they had assumed a greater self-advocacy role, and therefore perceived an urgent need to educate themselves on available resources and services. Despite being highly knowledgeable about the mental health system due to past volunteer work, Riley described the persistent, and often tiresome, effort and determination required to access necessary information and support:

I was just definitely left on my own. I didn't really even know what I could access or what there was to access. It was just very difficult and stressful, because even as someone who has a lot of knowledge about how the systems work and how to access care, it was still very frustrating and took a long time. I feel like if I didn't know about services, I would have just given up on trying to find stuff.

Many participants agreed with this sentiment, and emphasized the importance of self-advocacy



as an emerging adult. Having to continuously *prove* the legitimacy of personal mental health challenges, James retold the harrowing experience of trying to access school-specific mental health services following the loss of a close friend to suicide:

Trying to navigate academic accommodations and trying to secure mental health resources [...] was a process of just advocating for myself to just really like finish my work and go through that. They weren't very helpful with that to be honest. They weren't very understanding. They needed like hard evidence of what had happened. Which was just hurting me more. [...] The system was distrustful of my experience and it didn't really trust me to handle my own mental health or to know what was best for me.

Unfortunately, newly-acquired autonomy was often accompanied by additional pressure and responsibility. Many participants described feeling blamed for their mental health challenges — particularly when treatment was found to be ineffective. Kayla shared her experience of *exhaustion*, *frustration*, and *guilt* after trying several unsuccessful therapeutic interventions:

I felt like after going through so many areas of treatment, it's just tiring, and you feel fundamentally broken when it doesn't really work after so long. And then when it doesn't work, [health professionals and family members] think it's your problem.

Participants alluded to a greater onus placed upon TAY to *fix* themselves upon entering adulthood. A prime example of this, James discussed being reprimanded by several care providers who attributed poor psychosocial functioning to a perceived lack of self-care:

When you're a quote/unquote "kid" and you're in youth care, you are not really responsible for yourself or your care. But at the same time, that means that your opinion is often not heard or is not as valid as your healthcare professional, specifically if they're more clinically driven. And so it's either easy to feel invalidated or to feel disempowered in that experience because you feel kind of like a marble that's just being bounced around by professional and medicalized terminology. And then when you transition to — I guess — young adult care, I would say that it's kind of the exact opposite. Especially since like typically you're more well-versed with the medical jargon, it's like the things they're saying to you aren't as insightful anymore, and there's definitely more of an onus on you to fix yourself. [...] And it's almost like there's a perceived lack of responsibility on your part in taking care of yourself, that puts you there in the first place. It feels like it just furthers mental health stigma. It feels like things are all my fault, and if I just did things better, I would feel better.

Such condescension and lack of empathy, when combined with increased responsibility, caused

some participants to withdraw from adult services, or prevented them from acquiring such supports in the first place. Furthermore, the monotony of inpatient adult care was cited as so untherapeutic, that is discouraged several TAY from continuing to seek help. Jordan discussed how limited engagement with health professionals and a reduction in unit-based psychiatric programming led to the perception that adult patients were less valued than paediatric patients:

When I was on the [paediatric inpatient mental health unit], the staff were around and they kept you busy during the day, as opposed to like as an adult [...] where there's nothing really for you to do. There are a few groups, but when you're there for a long period of time, the groups are the same.

Participants highlighted the importance of first impressions, stating that if the intake process was overly arduous, or if they had an unpleasant encounter with a care provider, they were unlikely to access the same service a second time. Many discussed an overall loss of faith in the mental health system, owing to the repeated dismissal of their concerns. Having been sent away from countless services without any treatment or follow-up plan, Maria shared that she consistently hoped her troubling symptoms could be attributed to a physical health condition, so that she would be appropriately cared for:

I always hope there's something physical at this point that explains everything. So, like, if I go to the hospital and am throwing up, I hope there's something physical they can fix and it's not just a panic attack. [...] With doubt, there's no trust — that's how I've felt. [...] I've had a really negative experience where [health professionals] always doubt how I feel. [...] And as soon as someone shows any doubt in me, my trust is lost. [...] With the Emergency Department, it's almost like they roll their eyes at everyone who walks in.

While most participants perceived their transition experience to be negative, several felt that the process of taking photographs, completing written reflective exercises, and engaging in group dialogue helped them to recognize some less obvious positive outcomes, including more diverse treatment options, increased involvement in care decisions, and a heightened sense of self-efficacy. This shift in perspective facilitated Mitch's recognition of healthy personal coping strategies, which had been adopted in response to transition-related stresses:

I really had a hard time taking photos and thinking of something to take a photo of because like this week was supposed to represent like positivity, and for me [...] I felt like nothing positive came from me leaving the paediatric programs and transitioning into the adult ones. I couldn't think of anything positive, but the one thing I could think of is that it really forced me to focus on my self-care.

**Support.** Enhanced independence only increased participants' desire for emotional support from health professionals and personal allies. Many discussed the difficulty associated with securing care providers and services that were the right *fit*. For Maria, finding a Psychiatrist and a Social Worker that met her needs required a great deal of persistence. Having developed a laundry list of negative experiences, Maria was genuinely surprised when she finally happened upon an appropriate *match*:

I think for me it was all just pure luck. It took a couple of, like "this isn't the right fit", which was a waste of time and eventually like led me to better things. But it definitely took me a couple of years to find the right Psychiatrist, and to find the right counsellor that I bonded with. [...] It was a matter of trial and error.

Stemming from the ageist and condescending attitudes of many care providers, such as those described above, participants typically aligned with younger, more progressive health professionals who were attuned and empathetic to the interests and priorities of the TAY demographic. Riley emphasized the importance of relatability when selecting an appropriate care provider:

Once I went and saw [the Psychiatrist], it was pretty disappointing. [...] He was an older man and obviously hard to relate to as a 13-year-old, like "I'm not really sure what I'm supposed to say to you". I kind of told him how I had been anxious [...] but coming from more of a psychiatry perspective, he wasn't really the best talker. It was mostly just "alright, well these are some of the things we can do for you, if you want". But then we decided that wasn't a route I wanted to take.

Alluding to similarly frustrating experiences, participants shared how the dismissal of TAY concerns often prevented the establishment of strong therapeutic relationships necessary for treatment and rehabilitation. Even as an adult, James received little to no psychosocial support until after a suicide attempt that resulted in hospitalization:

It was only really after my [suicide] attempt, that my mental health concerns were taken seriously, which felt even shittier. Because I was like “oh, this is what it takes for you to recognize this — me being a liability to your image, essentially”. Which felt like another slap in the face.

Also feeling that her concerns had to be *justified* to be considered valid, Maria was regularly questioned about events from her distant past, as clinicians attempted to rationalize present psychiatric symptoms:

It’s not present-centred. [...] I found that like as a kid, it much more was, because it was more recent. But as an adult, they’re like “when did it start?” [...] Recently I had a new Psychiatrist, and it was just a two hour session of like “were your parents in the army?” It was just like *so* far back. This is another really good example of them just like wasting time and like looking at history. My Dad smokes, and so [the Psychiatrist] was like “does he smoke around you?” [...] and then he was like “does that bother you?”, and I was just thinking “this is so irrelevant!” So we spent 25 minutes on this topic that had *absolutely nothing* to do with anything, until finally they’re just like “oh, we’re just looking for an explanation”. But sometimes there just isn’t one!

Many participants shared such vexations, having encountered several health professionals who were determined to find meaning in unrelated or ordinary experiences from their childhood. Fishing for such explanations made TAY feel that any current self-identified issues were not important enough to capture the interest of their care providers. Equally patronizing, Mitch described how religious dogma perpetuated by spiritual advisors and Chaplains was often more harmful than helpful for TAY with mental health challenges:

I think a lot of times when you try to get religious people involved [...] they’re just like trying to sell whatever their religion is to you. [...] I don’t go to church really, but I went to a [faith-specific] school until I was like 14, and my parents are [of that same faith]. So, it was like the worse my mental health got, the more I steered away from religion because [...] they’re very judgey [*sic*], and they just believe if you go to church, that’s going to solve all of your problems. And I’m just like “that’s not true — it’s only a building”. You can call it whatever you want, but it’s a building.

In response to such pervasive apathy, oversight, and trivialization, Alex recommended that as health professionals age, they should be required to demonstrate continued competence — kept abreast of the latest treatments and therapeutic techniques, and held accountable for any educational advancements in the mental health field:

There are a lot of doctors who are very old. You have to go through school for a long time. I think they should also be given — you know how like when you get old you have to take your driver's test every so often to prove that you're still able to do it — I think doctors should have to do that too. Because even now, the biggest thing in my brother's life is like his fights with friends [...] and yeah, you're 12 and obviously you have very different priorities in life, but that doesn't mean you just brush them off. [...] And I feel like a lot of people in the healthcare system don't understand that. Like, yeah it turned out to not be a big thing for you, but you have the experience and have had the time to look back on that, whereas a 12-year-old can't because that's all they know.

Having encountered such unsupportive care providers, many participants felt they could not be open or honest about their thoughts or emotions. Particularly fearful of policies and practices related to disclosures of abuse, self-harm, or suicidal ideation, TAY reported having withheld information to prevent hasty, extreme, and sometimes unnecessary reactions by care providers. Mitch and Ellie discussed how censorship provided emotional protection, but may have also jeopardized physical safety:

Mitch: People don't really get it, because if you say it out loud — like even if you say it to a Therapist or something — they're like "oh my god, we have to get this kid on suicide watch!" "We have to lock him up!" Or, "hide the knives!" [...] And I'm just like "no, that's not how I feel". Like I don't want to be here sometimes, but at the same time I know I can't do anything about it, so it's like you're trapped in your own life. [...] I just worry that [...] they're going to take away my rights, they're going to take me out of my house, they're going to make me stay in a safe place so I don't hurt myself. I'm kind of worried about what they'll do, so I don't really tell people if I'm feeling that way. I just wait until it passes.

Ellie: I definitely hide things that should be talked about. That might just be because of past experiences with getting help. When I did disclose things, they took it in a way, and they had to bring my Mom into the room, and then they had to be like "are you going to tell your Mom that you're going to hurt yourself?" "Or are we going to tell her?" And I'm like, "I don't want to have this conversation" and I thought by me telling you that, you'd be able to help me. But now it's just really distressing. I mean I understand that you have that duty to report and protect me, but just the way that that went about several times, I just had like really bad memories of that. So I think that has kind of prevented me in adult services from disclosing certain things. [...] You want to disclose so that you can get better help, and to go to different services and access different supports, but you don't want to because you're not really sure if you have the strength to deal with that painful situation again.

All participants agreed on the importance of having a strong clinical advocate, whether or not they had been fortunate enough to acquire one themselves. Wishing for more comprehensive

care management, James concisely captured the inherent value of professional allies and support networks within the mental health system:

To be able to have that experience where somebody's like in your corner and on your side advocating for you, would be highly beneficial for people transitioning.

Agreeing that the *fit* of a particular therapeutic intervention is more so determined by one's rapport with the practitioner, than it is related to the service design or treatment model, participants engaged in a lively discussion about the qualities and characteristics embodied by an *ideal* mental health care provider. While seeking unconditional positive regard, validation, and a non-judgemental approach, TAY also desired someone who was knowledgeable, firm, and would hold them accountable for their actions. Kayla provided an example of such attributes when describing the incredibly positive relationship cultivated with her previous Social Worker:

When I finally found my Social Worker that I saw for almost two years [...] she was just like really, really supportive, and she like didn't judge anything that I did, and wasn't disappointed if I like had engaged in symptoms or whatever, and she like had advocated so much for me. She was the one who realized that I had [a personality disorder] in the first place, and was the one who told me to tell my Psychiatrist. [...] She was just like very kind and supportive, and understood what I was going through — like school stress and stuff like that. And she would gauge what I needed that day. Whether I needed tough love or someone to just be like “get your shit together”, or whether she could just validate — like if I was struggling — and be like “this is okay, it's not anything you did”. [...] And she kept me accountable. So when I'd leave the session, she would make sure I had like little goals to stay on track, and she would let me email her if I was going to use a behaviour. And she would tell me “I'm not necessarily going to reply, but you can email me, and I'll read it”. So it was nice knowing there was like one person who believed in me and my ability to do better. [...] Seeing her once a week was a good constant in my life.

Unfortunately, many participants were not so lucky as to have received this level or quality of assistance. Alex spoke about having to rely on her peers and younger sibling, because those well-positioned to advocate on her behalf — such as parents or care providers — did not assume a supportive role. Wishing her parents were more knowledgeable about the psychiatric field, Alex advocated for family education that would equip adults with the skills necessary to help TAY cope with mental health challenges:

My youngest brother and some of my friends were supporting me, but everyone else who was older — the people who *should* have been supporting me — weren't. [...] I feel like parents every so often should be given like a 'crash course' on how to be a supportive parent. Like how to be supportive from far back, but also be there when your kids want you to be.

Riley, whose parents actively participated in adolescent treatment, discussed how family inclusion was largely beneficial, as it provided the opportunity to learn more about mental health care:

My Mom would come to [the group therapy sessions]. [...] She came, and she would sit, and they would do their parenting group while we did our kid's group. And that was nice, that was supportive, but at the same time, my Mom has her own mental health issues, so it was kind of interesting. She would *try* to help, but also didn't want to acknowledge her own issues and stuff. So it was kind of a bit stressful for me, in that sense. But, at the same time it is always nice to have support from your parents.

Sadly, a continued reliance upon parents/guardians who maintained more active involvement in their child's care, caused some participants to experience an extreme sense of guilt. Still living in their respective childhood homes, Mitch and Ellie described feeling like a *burden* — particularly when several different treatment strategies proved unsuccessful:

Mitch: They're *very* involved because my mental health kind of gets in the way of everything. [...] I have a few different anxiety disorders, so it's like, because of my anxiety I'm not able to drive, I'm not able to keep a full- or part-time job, or anything like that. [...] I have a lot of guilt about it, and I feel really bad. Like my parents dropped me off here tonight, and I'm like "thank you, thank you" because I feel like shit about it. All my friends have jobs, they go to school, they have cars, what am I doing wrong here? I feel like I'm trying, but every little step I make — well it looks like a little step, but it's *huge* for me.

Ellie: I can relate to that guilt, though. Like having to ask for rides, because I'm too anxious to drive. And with my Mom — it just feels like you don't want to put any of that burden on them but you know that if you don't get to do any of those things, you're not going to be helping yourself.

A lack of appreciation for the severity of TAYs mental health challenges, and the many ways in which they impact daily functioning further exacerbated such guilt. After an emergency appendectomy, Mitch described how his family and friends were far more supportive of his acute physical condition, than his equally debilitating chronic psychiatric symptoms:

Mitch: When eventually I had healed from my surgery, I was sad that I was better. [...] Just because I had my appendix out, I felt like people had validated my pain. And everyone was like, oh “how’re you feeling? How’re you feeling? How’re you feeling?” And I was kind out like, “you know, when I was going through all of this mental health stuff, you guys didn’t give a shit about how I was feeling”. But now that it’s physical health, everyone’s there for you, everyone cares. So when I finally did heal physically, I was like “well, fuck”.

Craving increased choice regarding the involvement of family during the transition process, Kayla wished that her parents had possessed a heightened level of awareness regarding her treatment, but also would have preferred their detachment from care decisions:

For me, I would want support, but I wouldn’t want them advocating on behalf of me. Another thing is that my parents are very emotional and overbearing, and my Mom freaks out, so a lot of the times I have to censor what I say to her [...] because if she even senses a little change in my tone, it’s a whole “are you okay?”, “are you sure?” So I think I would feel much more comfortable being independent, because I’m just like more of an independent person. My parents are like *a lot*, so I think that affects my mental health.

While Riley favoured the increased autonomy associated with adult care, continued parental support was always greatly appreciated. Active listening and a demonstrated willingness to learn were cited as qualities that were most valued:

My parents were very supportive throughout. [...] Just about learning more. Because our parents, I feel like they don’t know a whole lot about mental health a lot of the time, because it wasn’t really a thing that people talked about, so my parents have been really good at listening to me and learning from me, which is great.

Finally, participants discussed the importance of being treated like a *normal* person. While TAY longed for their concerns to be validated and addressed, they were grateful for relationships — and particularly friendships — that were not centred around mental health diagnoses, symptoms, or treatments. The opportunity to engage with others without the pressures that accompany such intense conversations, afforded TAY the freedom to enjoy other aspects of their lives. Mitch described how his childhood friends served as a meaningful distraction from his anxiety:

It’s almost good in some ways that [my friends] don’t get my anxiety at all, because when I’m with them, I’m not someone with an anxiety disorder, I’m just me. I guess that helps a bit. It’s almost like they’re a distraction from it.



## Discussion

As indicated by participant narratives referenced above, issues explored through photo-elicitation discussions were deeply moving and impactful. The balanced nature of guided weekly photography topics facilitated a thorough reflection of the mental health care transition process for TAY (i.e., *the good; the bad; the vision*), resulting in the organic emergence of four central themes: (a) *Accessibility*; (b) *Coordination*; (c) *Independence*; and, (d) *Support*. This section provides objective commentary on PhotoSTREAM's comparative strengths and limitations, including its adherence to overarching study objectives, and opportunities for further investigation and collaboration. Implications for this research and its findings will be discussed at length in *Chapter III* to follow.

### Strengths

Feedback obtained both anecdotally, and through formal written evaluation, revealed high participant satisfaction related to the content and facilitation of focus group sessions. TAY appreciated the inherent flexibility of the study design, including the optional nature of many procedures and data collection tools. Furthermore, the use of diverse investigative methods — including photography, written reflection, and semi-structured dialogue — coupled with balanced weekly topics, afforded participants the opportunity to consider the phenomena of interest from varied perspectives. TAY involved in this study stated that they appreciated the combination of individual and collaborative exercises, as they were able to solidify their own thoughts before sharing such insights with others. Uninterrupted *gallery walks* also encouraged active listening, as they prevented individual participants from dominating conversation, or premature interjection that may have halted the development of an important idea.

Most notably, PhotoSTREAM participants appreciated the opportunity to establish meaningful connections with like-minded TAY. The validation of concerns and frustrations by

others left participants feeling *heard, understood, and supported*; thereby, resulting in a strong sense of camaraderie. Photographs and reflective prompts helped to naturally facilitate conversation, and gave everyone a reason to speak. Owing to the highly collegial, non-competitive atmosphere, participants described the focus group environment as *inclusive, comfortable, and safe*. TAY involved in this study consistently demonstrated empathy and compassion for their peers, and many expressed a desire to become more actively involved in local mental health advocacy initiatives following the completion of this project.

### **Limitations**

While implications derived from participant insights were undoubtedly eye-opening, the small sample size of this study greatly limits the generalizability of findings to other contexts. The relative lack of diversity within this sample was also not reflective of demographic characteristics pertaining to the broader population of TAY with mental health challenges. Considering the intersectional nature of vulnerabilities that may impact one's transitional experience, a more representative sample may have revealed nuances related to citizenship, socioeconomic status, or gender identity, for example. Additionally, focus group dynamics were highly influenced by the unique personalities, experiences, and motivations of participants and the facilitator. As such, it may be challenging to replicate the positive relationships forged between this particular group of TAY with another cohort.

Given that this project was undertaken by a graduate student, time and budgetary constraints impacted the accessibility of study procedures. With additional funding, monetary compensation could have been offered to participants who may have otherwise been unable to participate. Funds may have also been put towards professional transcription services, and the recruitment of one or more research assistants to support qualitative data analysis and focus group facilitation. Furthermore, financial support would have allowed for the multilingual

translation of study materials, as well as the purchase and distribution of digital cameras to all participants. Such changes would have fundamentally altered eligibility criteria; thereby, enhancing inclusivity.

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## CHAPTER III

### Nursing Implications

The PhotoSTREAM Project explored the aesthetic creations and personal narratives of eight transitional-aged youth (TAY) who have progressed from paediatric to adult psychiatric services within the province of Ontario. Participant photographs aligning with three topics — (a) *the good*; (b) *the bad*; and, (c) *the vision* — served to highlight a broad spectrum of mental health experiences across the transitional period. Images provided a balanced perspective regarding the strengths and shortcomings of existing services available to this age demographic, as well as opportunities for further growth, development, and innovation. Consistent with Wang and Burris' (1997) Photovoice method, photographs elicited critical reflection and dialogue pertaining to the phenomena of interest; thereby, revealing four overarching themes: (a) *Accessibility*; (b) *Coordination*; (c) *Independence*; and, (d) *Support*. Such findings contribute to contemporary nursing and interprofessional health literature advocating for the prioritization of emerging adults' unique psychosocial needs (Brownlie et al., 2017), through the creation, reformation, and evaluation of mental health-promoting policies and practices.

As clinicians, leaders, and advocates, nurses have driven meaningful emancipatory change for vulnerable populations throughout history, and are thus ideally-suited to support a paradigmatic shift in the provision of TAY mental health care (Fontana, 2004). Accordingly, this chapter summarizes implications for nursing practice, policy, education, and research, in order to guide pervasive and sustainable advancement in this field. Inspired by the lived experiences of PhotoSTREAM participants, TAY perspectives have been thoughtfully integrated into actionable recommendations that transcend various care domains, and will therefore necessitate collaborative efforts among professionals, organizations, and broader sociopolitical structures. It should be noted, however, that the solutions proposed are idyllic — intended to

provide a high-level overview of possible changes. Application of such suggestions would require thorough consideration of nuanced bureaucratic complexities, including ever-fluctuating government priorities and budget allocations.

### **Clinical Practice**

Consistent with the five tenets of the therapeutic nurse-client relationship espoused by the College of Nurses of Ontario (2019), participants craved meaningful connections with mental health care providers rooted in empathy, trust, respect, professional intimacy, and an equitable distribution of power. Described at length in the *Findings* section of the preceding chapter, support and guidance by professional allies were perceived to be inextricably linked to a smooth and successful transition process. As such, participants advocated for the development and implementation of transition-specific roles to assist all TAY with mental health challenges, irrespective of psychiatric services acquired. Conceptualized as an interdisciplinary team assigned to those approaching the paediatric-adult care nexus, participants agreed that proactive planning with informed professionals would help to mitigate the confusion and trepidation associated with such a dramatic change. Operating as a single unit and working toward common treatment goals, *transition teams* may naturally result in more effective communication and collaboration among care providers. By mitigating ambiguities, oversights, and duplicated efforts associated with existing referral processes, a team-based treatment model could potentially streamline the progression from paediatric to adult psychiatric services. When asked which professional would be best-suited to lead such a team, participants felt that an Advanced Practice Nurse with extensive knowledge and clinical experience relevant to TAY mental health would be most appropriate, particularly given the anticipated care coordination and case management functions associated with this role.

While the desire for holistic, comprehensive transition support was made clear,

participants strongly endorsed that a heightened emphasis be placed upon TAY-led approaches. Valuing flexibility and customization, participants envisioned services that catered to individual needs, rather than adopting standardized *one-size-fits-all* treatment protocols. Having encountered several invalidating and disempowering professionals and services throughout their care trajectories, participants also discussed the importance of exercising personal autonomy. The opportunity to engage in decisions regarding one's own treatment was considered a determining factor when evaluating the *fit* of care providers or therapeutic interventions. Also deemed significant, was the establishment of care consistency and reliability. Several participants discussed the time and energy required to build authentic connections with mental health professionals. For TAY who had been habitually disappointed by psychiatric services, many were understandably hesitant to embrace the openness, honesty, and vulnerability necessary for their recovery. As such, sustained patient-provider relationships should be prioritized, as a strong rapport was cited by participants as having facilitated increased treatment engagement and improved mental health status. Conversely, unpredictability was described as having heightened levels of fear and anxiety; thereby, thwarting rehabilitative efforts.

Many TAY involved in this study also advocated for more welcoming and inclusive admission processes across psychiatric care settings. During focus group sessions and individual interviews, participants detailed countless traumatizing experiences that ultimately instilled a deeply-rooted fear of professional psychosocial support. The convoluted, highly impersonal, and institutional nature of most intake procedures have only perpetuated the stigmatization of mental health challenges. For many participants, help-seeking behaviours were actively avoided until an acute state of crisis was reached, at which point they were forcibly brought to their local Emergency Department. Once there, it was not uncommon for participants to encounter security guards, locked padded cells, and several-day waiting periods in hospital hallways before being

admitted to an inpatient psychiatric program, or referred to an appropriate community resource. TAY told a recurring tale of needing to *hit rock bottom* — a functional decline that not only prompted their willingness to accept professional support, but was also frequently perceived as a prerequisite for their concerns to be deemed worthy of such support.

## **Policy and Legislation**

Significant legislative reform and policy development will be required in order to enact necessary clinical practice changes, such as those outlined above. Already in effect at several leading psychiatric facilities, including the Centre for Addiction and Mental Health (2019) in Toronto, participants strongly advocated for the restructuring of rigid age classifications guiding psychiatric service delivery. Arguing that treatment should cater to developmental stage rather than chronological age, participants requested the implementation of a third category intended specifically for TAY, situated between paediatric and adult mental health care divisions. Envisioned as extending from ages 16 to 25, services for this demographic would overlap with child/adolescent supports available to individuals under 18, as well as those targeting adults aged 18 and over. This intermediate step would allow emerging adults who fall within more than one category to choose services that best align with their psychosocial maturity, care priorities, and treatment goals. Young people who would prefer to progress directly to adult care may do so, while those seeking a more gradual transition process may access TAY services at any time within a ten-year span. Such flexibility is particularly advantageous for treatment-naïve youth experiencing their first psychiatric episode during the transitional period. In such cases, TAY-specific services may provide a therapeutic cushion that eases one's entry into the exceedingly complex mental health system.

The reallocation of government funding to community services rather than inpatient psychiatric programs was another recurring topic of discussion, as many TAY felt that greater

emphasis should be placed upon preventative care measures and early intervention strategies compared to downstream stabilization and management of severe, highly debilitating mental health challenges. Many participants were not considered eligible for desired psychiatric supports until they had experienced an acute crisis episode that demonstrated the legitimacy of their concerns, and finally initiated referrals to appropriate mental health professionals. The advent of more widespread and robust health-promoting resources was thought to potentially reduce the prevalence of risky self-injurious behaviours and suicide attempts by TAY (Cleverley et al., 2018; Sukhera et al., 2017). Increased investment in publicly-funded services would also improve the availability and quality of community supports; thereby, indirectly easing the financial burden incurred by many TAY left with no choice but to pay out-of-pocket for private mental health care.

Policy change related to the involvement of allies in psychiatric treatment was also discussed, as many TAY described relying on at least one non-relative throughout their mental health journey, whether for advocacy, guidance, or emotional support. Unfortunately, common regulations and policies pertaining to such inclusion are limited to immediate family members or legal guardians. For several participants in this study, parents or other blood relatives were not only considered unhelpful, but were also thought to have actively contributed to existing mental health challenges. While close friends, mentors, or romantic partners were often described as playing a highly significant role in TAYs recovery journey, their formal involvement in treatment discussions was seldom permitted. Consistent with a TAY-led philosophy described above, participants in this study felt that emerging adults should have the authority to identify the specific support person(s) they wish to have included within their own circle of care.

A final implication relevant to health policy, concerns the secure access and distribution of TAYs clinical records. While many participants stated that information pertaining to their

treatment was shared among mental health care providers within the same organization, external professionals were often not privy to such findings. As a result, incomplete health histories and disjointed communication between clinicians slowed the progress of ongoing therapeutic interventions. Due to an unfamiliarity with TAYs past medications, therapies, and diagnoses — including those that were ruled out — some participants were required to unnecessarily repeat treatment regimens that had already been deemed ineffective. Frighteningly, ignorance of high-risk behaviours, critical incidents, or previous hospitalizations, also bore the potential for more devastating consequences, including physical harm to oneself or others. While retrieval of personal health information would require the formal consent of TAY or an appropriate substitute decision maker, participants expressed a clear desire for their clinical records to be more readily accessible by the professionals entrusted with their care. Furthermore, an enhanced knowledge and awareness of one's own health history was seen as a source of empowerment for TAY with an otherwise-limited sense of personal autonomy.

### **Education and Pedagogy**

Unfortunately, the inherent fluidity of mental health status is not common knowledge. Typically thought of as the absence of mental illness, a common misconception exists that *healthy* people do not experience such psychological variation. The truth, though, is that everyone encounters occasional cognitive, mood, and expressive abnormalities that may impact daily functioning. However, when one's thoughts, feelings, and behaviours become problematic to the extent that they are no longer able to cope with intrinsic and environmental stressors independently, individuals may benefit from professional support irrespective of a formal psychiatric diagnosis (American Psychiatric Association, 2013). It is critical that those struggling receive help before symptoms or associated maladaptive coping mechanisms become unmanageable. A fundamental shift in mental health education is required to increase public



knowledge and awareness of basic psychiatric principles, and particularly those unique to the TAY population. Such efforts are dual-purpose in their promotion of psychosocial health and wellbeing, and simultaneous reduction of societal stigma and intolerance (Richards & Vostanis, 2004).

While children and adolescents would undoubtedly benefit from the integration of comprehensive mental health teaching into standard academic curricula, it is critical that educators and clinicians become more knowledgeable as well. Since mental health challenges among TAY commonly impact academic performance and social interactions with peers, participants felt that comprehensive training for teachers and school administrators regarding early recognition and assistance may prevent emerging adults from *falling through the cracks*. Furthermore, the creation of a dedicated *transition worker* position assigned to all secondary schools, may facilitate a smoother progression to adult psychiatric and social supports following graduation. For students with mental health challenges choosing to pursue continued studies at a college or university, this role may prove especially useful when liaising with post-secondary psychiatric services. Many participants encountered considerable difficulties when attempting to secure suitable education-related mental health resources and academic accommodations. Accordingly, the endorsement of individual learning needs and appropriate modifications by a recognized in-school mental health professional, may expedite such processes. Through the establishment of a certification course with tailored subject matter, the transition worker position could likely be assumed by a Registered Nurse and/or Guidance Counsellor — roles which are permanent fixtures in most secondary schools throughout the province, and already provide informal mental health support to students in need (Laforêt-Fliesser, MacDougall, & Danaher, 2015; MacDougall, Laforêt-Fliesser, & Columbus, 2015).

Tailored assessment and intervention strategies for TAY with mental health challenges

will require the implementation of similar training programs for healthcare providers, and particularly those practicing outside of the psychiatric field. Mental health is a pervasive issue that infiltrates every discipline and care setting, and must therefore be integrated into core curricula for all budding clinicians. Having evolved significantly over recent decades, public knowledge regarding psychiatric diagnoses and treatment options is limited at best, and healthcare providers are no exception. Often deemed the *black sheep* of medicine, health professionals themselves perpetuate fallacy and stigma pertaining to the psychiatry specialty (Lieberman & Ogas, 2015). Thus, it is necessary to enhance understanding and garner interest in mental health among care providers, to promote continued therapeutic advancement in this field. Clinicians must be prepared to identify signs and symptoms of psychological distress or dysfunction, and to respond swiftly and appropriately to urgent disclosures, regardless of their place of work.

When discussing preparatory measures for TAY approaching the transitional period, participants requested the advent of a seminar or class that would provide a general overview of common responsibilities associated with adulthood. An enhanced familiarity with simple tasks such as budgeting, scheduling appointments, navigating public transportation, or preparing meals was believed to significantly reduce anxiety concomitant with this transition. Owing to the unique interests, needs, and priorities of the TAY demographic, study participants also envisioned a peer mentorship model for emerging adults aging out of paediatric mental health services. The opportunity to learn from relatable youth who underwent a similar transition was highly appealing to participants who felt that many health professionals had become jaded and lost their compassion for those encountering such monumental change for the first time. Much like existing roles such as Peer Support Workers or addiction-related Sponsors, a *TAY Peer Mentor* would offer allyship, guidance, and reassurance to those navigating the nuances

associated with the transition process. While undoubtedly helpful for the recipients of such mentorship, recruitment of peer volunteers would require careful consideration of emotional readiness, as well as coaching regarding the establishment and maintenance of professional boundaries in order to prevent compassion fatigue, vicarious trauma, or burnout (National Child Traumatic Stress Network, 2011).

### **Research and Scholarship**

Future research pertaining to TAY mental health requires the continued use of youth-led participatory action research (YPAR) approaches that prioritize youth engagement and collaboration (Ozer, 2016). Extending beyond consultative efforts, active involvement in study design, data collection, analysis, and knowledge dissemination activities affords youth the opportunity to meaningfully contribute to scientific discovery and emancipatory change. Furthermore, the use of progressive visual and arts-based methods enhances creative expression; thereby, illuminating ideas and perspectives not easily disclosed through verbal communication, whether due to deliberate suppression, limited vocabulary, or confusion and uncertainty. Participants articulated a desire for the TAY voice to be integrated into mental health advocacy and awareness initiatives, to ensure accurate representation of this age demographic and their unique needs, while also preventing exploitation.

### **Conclusion**

The study described in this manuscript builds upon existing nursing and interprofessional health literature seeking to understand the experiences of individuals who face systemic barriers to mental health service access and utilization (McGrandles, & McMahon, 2012), while also contextualizing such experiences within the period of transformational change that occurs as youth transition from adolescence to adulthood (Sukhera et al., 2015). Possessing both practical and heuristic research implications, participant photographs served to illuminate contemporary

injustices, and promote opportunities for ongoing exploration. Study findings and accompanying recommendations can be utilized by nurse leaders to challenge existing hegemony by embracing YPAR approaches. That is, by demonstrating an unwavering support for TAY-led efforts, health professionals may effect more meaningful change for this vulnerable population than by assuming an advisory role.

Through evocative storytelling and community advocacy, PhotoSTREAM participants have served as change-agents in the exposure of psychiatric service delivery gaps impacting TAY; thereby, achieving aesthetic resonance and influencing meaningful sociopolitical reform. While the insights and abilities of young people have long been dismissed (Clark et al., 2008), an opportunity exists wherein youth are afforded autonomy and self-determination in decisions regarding their care. Through involvement in the PhotoSTREAM Project, the perspectives of TAY were not silenced, but rather, honoured and appreciated — setting a new precedent for youth-led mental health legislation and clinical practices.

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## Seeking Study Participants For



# The PhotoSTREAM Project

## Supporting Transition-Readiness for Emerging Adults with Mental Health Challenges

***How do youth living with mental health challenges experience the transition from paediatric to adult psychiatric services?***

This study seeks to answer this research question through a combination of photography, focus group discussions, and individual interviews. If you're interested in sharing your perspectives regarding the strengths and shortcomings of existing mental health services, please consider participating. Your contribution will help to inform more seamless and supportive care transitions that meet the unique mental health care needs of Canada's young adults.



## Are You Eligible?



Fluent in English



### Young Adult, Age 18-24



Received Mental Health Care in Ontario as a Child (Under 18)



### Experienced Mental Health Challenges as an Adult (18+)



### Access to a Digital Camera or Smart Phone



### Willing to Participate in Audio-Recorded Group Discussions

## For More Information

**Contact Brianna Jackson, RN, BScN**



WWW.PHOTOSTREAMPROJECT.ORG




## Appendix B


### **LETTER OF INFORMATION**

*The PhotoSTREAM Project:  
Supporting Transition-Readiness for Emerging Adults with Mental Health Challenges*

#### **Graduate Student Researcher**

Brianna Jackson, BScN, RN  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University  


#### **Supervising Faculty Members**

Dr. Kim Jackson and Dr. Richard Booth  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University  


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#### **Invitation to Participate**

You are invited to participate in a research study that will use photography to explore the mental health care experiences of young Ontarians. This project is intended for adults between the ages of 18 and 24 who have previously, or are currently living with mental health challenges, and who have interacted with Ontario's mental health care system as both a child/adolescent and as an adult. A total of 10 to 15 participants will be enrolled in this study.

#### **Study Purpose**

The purpose of this study is to learn about the transition from paediatric to adult psychiatric services, and more specifically, the strengths and barriers that impact quality and continuity of care, so that recommendations can be made for more effective and supportive transition policies and practices.

#### **Time Commitment**

It is expected that you will be involved in this project for one month. During this time you will take part in three weekly 90-minute focus group sessions (guided group discussions with all study participants), and one optional 30-minute individual interview; each of which will be facilitated by the graduate student researcher. All focus group sessions will take place in a private meeting room within a centrally-located community space in downtown London that is easily accessible via public transit. Between sessions, you will be asked to take photographs at your convenience. Any participants interested and willing to take part in related post-study knowledge dissemination activities, such as publications, presentations, or showcases, are invited to remain involved beyond the one-month mark.

## **Procedures**

Upon providing verbal consent to participate, you will receive an orientation handout via email. This document will highlight what you can expect from focus group sessions, as well as some quick photography tips, and personal wellness strategies.

Formal written consent will be collected from each participant at the beginning of the first focus group session, at which time you will also be asked to complete an optional demographic survey. Your responses to this questionnaire will be kept anonymous, and are meant to provide general information about the group of study participants, rather than you as an individual. Next, all participants will engage in some simple icebreaker activities, and establish a set of shared group expectations and community norms for the duration of the project.

Each week, you will be encouraged to take photographs that reflect a particular topic related to your mental health care experiences during the transitional period. Focus group sessions will involve individual reflection and collaborative discussions about these photographs, as well as sorting, titling, and captioning activities that will aid in the discovery of overarching themes and patterns.

After the completion of focus group sessions, you will be invited to attend an optional 30-minute individual exit interview, should you wish to share any insights or perspectives outside of the peer group environment. Such conversations may contribute to a richer understanding of your unique mental health care journey. Individual interviews will take place in a private meeting space either on the Western University campus, or alternative community location of your choice. At that time, you will also have the opportunity to review all of your photographs, and provide additional clarification about your thought processes and artistic decisions. Finally, you will be asked to complete an optional program evaluation questionnaire to provide anonymous feedback about your involvement in the study.

## **Risks**

Given the sensitive nature of discussions regarding the mental health care system and personal experiences with psychiatric services, there is the risk that you may experience heightened emotional sensitivity. All participants will be invited to take breaks during focus groups and interviews as needed, and encouraged to engage in health-promoting self care practices to enhance personal wellbeing. Should you experience emotional distress at any point throughout the duration of the study, you will be referred to appropriate local mental health and crisis services based upon your individual needs. The graduate student researcher is a Registered Nurse with clinical experience in both paediatric and adult mental health care, and will provide ongoing guidance and support to all participants.

## **Benefits**

While you may not experience any direct benefits related to study involvement, the participatory and collaborative research design may promote a sense of empowerment, and opportunities for meaningful social interaction. Furthermore, information gathered may result in broader societal benefits, including enhanced awareness of emerging adult perspectives that may ultimately be integrated into mental health policies and clinical practices.

## **Withdrawal**

Participants may choose to withdraw from the study at any time. If you wish to have your information removed please let the graduate student researcher know, and any personal data collected from the individual exit interview will be destroyed from our records. However, information obtained through focus group sessions or anonymous questionnaires will still be used, as the research team will be unable to identify individual participants' comments. No new information will be collected without your permission.

## **Privacy and Confidentiality**

Any information you share with us will be kept strictly confidential. Personal identifiers such as name, phone number and/or email address will be logged on an encrypted master list that is stored separately from all other study data. All electronic files will be housed on the Western University Network behind a secure institutional firewall. Paper copies of study materials such as demographic questionnaires, program evaluation forms, and photographs will be housed on the Western University campus, in a locked filing cabinet within a secure research office. While every effort will be made to protect your anonymity, please note that the collection of personal identifiers carries an inherent risk to your privacy and confidentiality, in the unlikely event of a security breach.

De-identified study data may be included in publications or presentations of study findings using a pseudonym, but direct quotes will never be shared without your consent. As per Western University policy, all study data will be kept in a secure and confidential location for a minimum of 7 years. Audio recordings of focus group sessions and individual interviews will be obtained with the express permission of all participants, and are to be used for data analysis purposes. All discussions will be permanently deleted from a secure audio recording device following the completion of the study, and stored on an encrypted memory stick.

All participants are expected to respect the privacy of their peers, and will be asked to sign a confidentiality agreement during the first focus group session. This document will serve as a written promise of non-disclosure, to prevent the sharing of personal information discussed within focus group sessions. While the research team will take all necessary precautions, we cannot guarantee that other study participants will respect your privacy and confidentiality.

If you tell us that you are at risk of harming yourself or others, by law we have a duty to breach confidentiality to ensure you receive the help and support you need. Similarly, if you discuss any current abuse or neglect of children, we are legally obligated to report the relevant information to the local child protection agency. Before sharing any such information, we will always discuss this with you first.

To oversee the ethical conduct of this study, representatives of Western University's Health Sciences Research Ethics Board may require access to study-related information in order to ensure all appropriate laws and regulations are followed.

### **Costs and Compensation**

There are no direct costs associated with this study, and every effort has been made to ensure that your participation does not pose any unnecessary inconvenience to you. While you will not receive monetary compensation for your involvement, please inform researchers if you anticipate any barriers to participation that may be mitigated through non-financial supports. Light refreshments will be provided during all focus group sessions.

### **Participant Rights**

Your participation in this study is entirely voluntary. Should you provide your written consent to participate, you retain the right not to answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study you will not be penalized in any way. You do not waive any legal right by consenting to this study.

### **Questions**

Study participants will receive a weekly check-in from the graduate student researcher over the phone or via email to ensure ongoing safety and engagement in the *PhotoSTREAM Project*, to offer guidance and support as needed, to troubleshoot any issues that may have arisen, and to remind you of the meeting time and location for the next focus group session.

Should you have additional questions, comments, or concerns about your participation in this study, please do not hesitate to contact Brianna Jackson, the graduate student researcher at [REDACTED]. You may also contact her research supervisors, Dr. Kim Jackson ([REDACTED] or [REDACTED]) or Dr. Richard Booth ([REDACTED] or [REDACTED]).

If you have any questions about your rights as a research participant or the procedures of this study, you may contact *the Office of Human Research Ethics* at [REDACTED] or [REDACTED]. The Health Sciences Research Ethics Board (HSREB) is a third party who oversees the ethical conduct of research studies at Western University. Everything that you discuss with the HSREB will be kept strictly confidential.

*This letter is yours to keep for future reference.*

## CONSENT

*The PhotoSTREAM Project:  
Supporting Transition-Readiness for Emerging Adults with Mental Health Challenges*

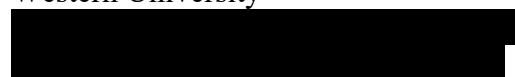
### **Graduate Student Researcher**

Brianna Jackson, BScN, RN  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University



### **Supervising Faculty Members**

Dr. Kim Jackson and Dr. Richard Booth  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University



Your participation in this study is entirely voluntary. As such, you are free to withdraw from the project at any time without consequence.

If you have questions about your rights as a research participant or the conduct of this study, you may contact *the Office of Human Research Ethics* at [REDACTED] or [REDACTED].

By signing below you agree to participate in the study described in the letter of information attached.

- ☐ Yes    ☐ No    I agree to be audio recorded during focus groups and individual interviews.
- ☐ Yes    ☐ No    I agree to the use of unidentified quotes in the dissemination of this research.
- ☐ Yes    ☐ No    I agree to the use of unidentified photographs for dissemination purposes.

\_\_\_\_\_  
*Participant Name*

\_\_\_\_\_  
*Participant Signature*

\_\_\_\_\_  
*Today's Date*

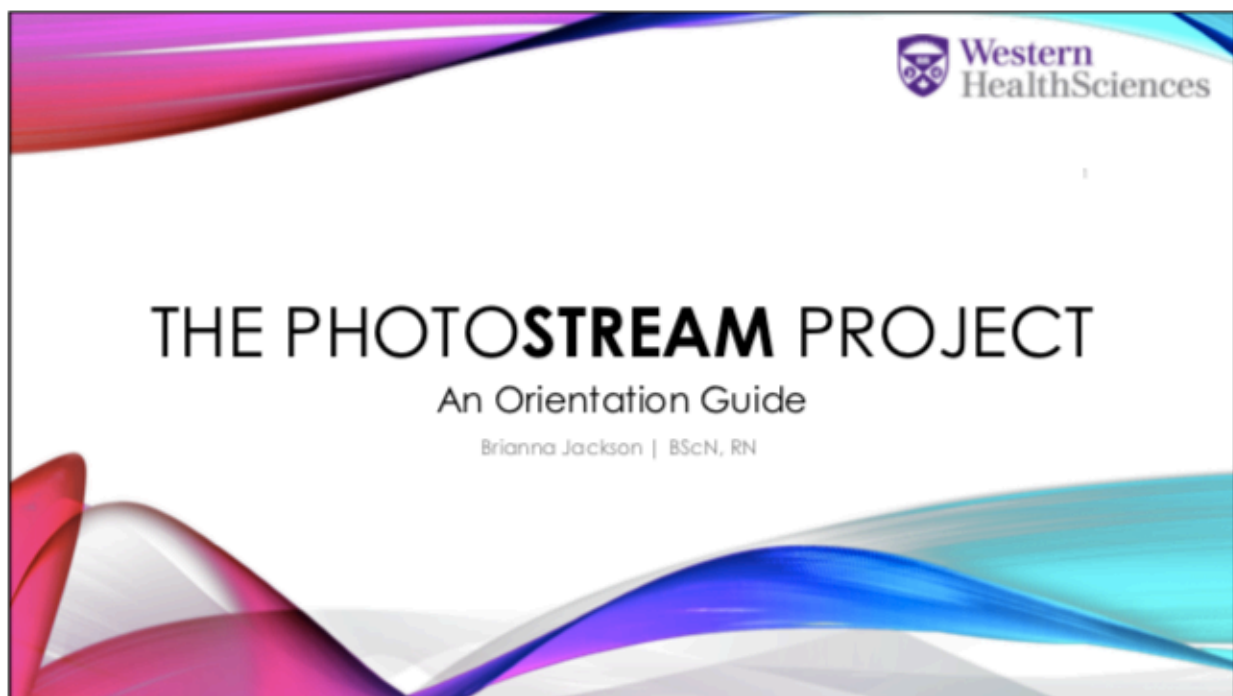
The researcher's signature below indicates that the letter of information has been shared and described to the participant named above, and their written consent has been obtained.

\_\_\_\_\_  
*Researcher Name*

\_\_\_\_\_  
*Researcher Signature*

\_\_\_\_\_  
*Today's Date*

## Appendix C



## THE PROBLEM


- The transition from adolescence to adulthood brings with it many new challenges and potential stressors that may negatively impact psychosocial wellbeing
- Young people between the ages of 15 and 24 experience higher rates of mental distress than any other age group
- Stability, consistency, and continuity of mental health care are of paramount importance for emerging adults
- Disjointed progression between paediatric and adult psychiatric services leaves many adolescents vulnerable to negative consequences, including social isolation, self-harm, substance use, and suicidal ideation
- Current evidence validates the need for clinical practice reform and policy revision to address this issue
- The perspectives of young people are consistently underrepresented in conversations regarding youth-oriented psychiatric program development

Wiktoria Jackson | BScN, RN

## THE PURPOSE

- The **PhotoSTREAM** Project seeks to address the research question: *how do youth living with mental health challenges experience the transition from paediatric to adult psychiatric services?*
- This study draws upon the PhotoVoice method, which utilizes a unique combination of photography, focus groups, and interviews
- Through individual reflection and meaningful group discussion, the research team hopes to gain insight regarding the strengths and shortcomings of existing mental health services, and opportunities for more seamless and supportive care transitions for emerging adults

Wiktoria Jackson | BScN, RN



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## THE PROJECT

- Independent photography based upon the following weekly topics:
  1. Positive experiences during your transition from paediatric to adult mental health care
  2. Negative experiences during your transition from paediatric to adult mental health care
  3. Your vision for optimal mental health care across the transitional period
- 3 weekly focus group sessions (90 minutes each)
- 1 optional individual interview (30 minutes)
- 2 optional surveys (5 minutes each)
- 1 optional data analysis meeting (60 minutes)

Biorena Jackson | BScN, RN

Biorena Jackson | BScN, RN

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## PHOTO**STREAM** AT-A-GLANCE

What can I expect?







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## GETTING STARTED

- Each week you will take photographs on your smart phone, digital camera, or other electronic device in preparation for the next focus group session
- These photographs should reflect that week's topic (outlined on the previous slide) in some way; however, creativity and abstract thinking are strongly encouraged!
- While you will be asked to submit all relevant photographs, please select only 1 or 2 that you would like to be printed and used to guide discussion during the upcoming focus group session
- You will be sent a link to a secure OneDrive folder, through which you can upload all photographs — this can be done directly if your device has wireless connectivity, or via an electronic cable or SD card to facilitate data transfer from your phone/camera to a computer with internet access

Brianna Jackson | BScN, RN



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## SHOWING UP

- Brianna will be in touch with you each week via phone or email, to answer any questions you may have, and to remind you of the upcoming focus group session
- Focus group sessions will take place in private (typically boardroom-style) meeting spaces with lots of space for you to move around
- When you arrive at the first focus group session, printed photographs will be sitting on the table, along with blank paper, sticky notes, pens, and markers — you do not need to bring any supplies with you, but may do so if it makes you more comfortable
- There will be complimentary refreshments available at each focus group session — please let Brianna know if you have any allergies or dietary restrictions

Brianna Jackson | BScN, RN

## DIVING IN

- Before the first focus group session begins, you will be asked to sign:
  1. A written consent form that verifies your enrollment in the study
  2. A confidentiality agreement that protects the privacy of all participants
  3. A photography release agreement that grants permission for your pictures to be used for research purposes
- You will have the opportunity to meet the other participants before completing any analysis of the photographs — we will begin by engaging in simple icebreaker activities, and establishing a set of shared group norms
- You are encouraged to take breaks as needed, and may leave the room at anytime

## FOCUS GROUP 1

- Consent, Confidentiality Agreement, & Photograph Release
- Demographic Questionnaire (Optional)
- Ice Breaker Activity
- Topic Overview: The Positives
- Written Reflection
- Gallery Walk
- Titling & Captioning
- Pile Sorting
- Assigning Thematic Labels
- Next Week's Theme: The Negatives

## FOCUS GROUP 2

- Review of Last Week's Themes
- Knowledge Dissemination Discussion
- New Topic Overview: The Negatives
- Written Reflection
- Gallery Walk
- Titling & Captioning
- Pile Sorting
- Assigning Thematic Labels
- Next Week's Theme: The Vision

## FOCUS GROUP 3

- Review of Last Week's Themes
- Knowledge Dissemination Discussion
- New Topic Overview: The Vision
- Written Reflection
- Gallery Walk
- Titling & Captioning
- Pile Sorting
- Assigning Thematic Labels
- Program Evaluation Survey (Optional)
- Celebration

## EXIT INTERVIEW (OPTIONAL)

- You will have the opportunity to participate in an individual interview — this is a good opportunity to share perspectives that may have been missed during focus group discussions, or that you may feel more comfortable sharing without other participants present
- Your photographs will be present during this interview to help facilitate dialogue — please feel free to discuss the thoughts or emotions that images evoke, or describe any deliberate artistic decisions you made (ex. lighting, focal points, special effects...)
- Brianna will also ask you about your mental health care transition experiences, but you are encouraged to share only as much as you feel comfortable

Brianna Jackson | BScN, RN

## ANALYTIC MEETING (OPTIONAL)

- Following the completion of focus group sessions and interviews, all participants will be invited to a supplementary data analysis meeting
- During this meeting, participants will work with the research team to determine overarching themes using various analysis techniques
- Study participants are traditionally excluded from data analysis activities; however, this study seeks to involve youth during every step of the research process
- There is no pressure to attend this meeting — it is simply an opportunity to contribute to the continued evolution of study findings
- All formal results will be documented in a letter that will be delivered to participants, regardless of their participation in the data analysis meeting

Brianna Jackson | BScN, RN

## KNOWLEDGE DISSEMINATION

- Consistent with this study's collaborative and participatory design, it is important that participants have the opportunity to provide input regarding the dissemination of study findings — this simply refers to sharing results with members of the community, including:
  - Researchers
  - Healthcare providers
  - Policy makers
  - General Public
- During focus group sessions, you will be asked to share how you would like study findings to be shared, and with whom
- Participants who would like to be involved in the ongoing development of knowledge dissemination initiatives such as publications, presentations, or showcases, are encouraged to do so, and will be kept informed of all plans

Bianca Jackson | BScN, RN

Bianca Jackson | BScN, RN

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## PHOTOGRAPHY 101

What should I take pictures of, and how?

## CREATIVITY

- Consider the 6 question words: who, what, when, where, why, and how
  - How do these words relate to your mental health care transition experiences?
- Think about the emotions you want your photographs to evoke, and how you can convey this to an observer
- Experiment with a variety of artistic effects, including the use of colour, movement, perspectives, contrast, size, light, shape, and symmetry
- Consider how you might convey other senses that are not traditionally represented visually, such as sound, smells, or physical sensations
- Try not to think too literally — use symbolism and abstract thinking to represent concepts in non-traditional ways

## LOGISTICS

- Explore the various effects that your phone or camera offers — now is your chance to try pressing all of those buttons!
- Carefully consider which photographs you would like to share with the research team and other participants — once photographs have been uploaded, they are deemed the property of Western University
- If you can't upload photographs to the OneDrive folder directly from your phone or camera via wireless connection, ensure you have a USB cable, SD card, or other secure method of transferring data from your electronic device to a computer with internet access
- Upload your photographs over a secure private internet connection, as public wifi can be easily hacked



## SAFETY & SECURITY

- While it is strongly encouraged that you refrain from taking photographs that depict specific people or organizations that were involved in your mental health care, should you choose to showcase recognizable people, locations, or belongings in your images, you must obtain informed consent from the individual whose face, body, or property you are photographing
- In the case of organizations, consent should be sought from someone in a senior leadership position, such as a manager, director, or coordinator, who has the authority to grant such permissions
- When engaging in weekly photography assignments, please take appropriate safety precautions, such as traveling with someone, informing others of your whereabouts, planning a safe route, considering transportation needs, weather conditions, and daylight hours, and maintaining a heightened awareness of your surroundings

Bikoreo Jackson | BScN, RN

Bikoreo Jackson | BScN, RN

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## ENHANCING WELLNESS

How can I prevent emotional distress?

## SELF-CARE

- The research team recognizes that discussing your mental health care experiences can be challenging
- During focus group sessions and interviews, you are encouraged to engage in self-care practices that help you remain calm and focused
- Colouring pages and fidget toys will be available for you to use freely
- You are encouraged to stand up, stretch, and walk around during focus group sessions, and are able to leave the room at any time
- Refreshments will be present throughout the entirety of the focus group sessions for you to enjoy
- Between focus group sessions, please make time for the people and activities that alleviate stress, and re-energize you!

Brianna Jackson | BScN, RN

## ASK FOR HELP

- Please inform the research team if at any point during the study you become emotionally distressed
- You will receive weekly check-ins via phone or email, at which time you may feel more comfortable disclosing new or worsening mental health challenges
- Brianna is a Registered Nurse with mental health care experience and can assist with immediate crisis intervention and stabilization
- You will be provided with a comprehensive list of community wellness resources at the beginning of the study, and will be referred directly to appropriate services if needed
- Your participation is entirely voluntary, and you may choose to take a break from the study, or withdraw entirely at any time, and without prior notice

Brianna Jackson | BScN, RN



# QUESTIONS?

Email Brianna at [REDACTED] for more information.



# THANK YOU!

Your participation is sincerely appreciated.



## Appendix D

### *The PhotoSTREAM Project — Weekly Focus Group Guide*

#### 1) Project Updates

- Remind participants of confidentiality agreement, and discourage use of personal identifiers during audio-recorded dialogue
- Check in with each participant individually
- Briefly recap last week’s focus group discussion and resulting themes — allow participants the opportunity to accept, reject and/or modify any new codes
- Address any questions or concerns pertaining to all participants

#### 2) Individual Reflection

- Invite each participant to look closely at the one or two photographs they selected for printing based upon the current week’s topic:
  - Week 1: Positive aspects of participants’ transitions from paediatric to adult mental health care
  - Week 2: Negative aspects of participants’ transitions from paediatric to adult mental health care positives
  - Week 3: Participants’ visions of optimal mental health care for transitional-aged youth
- Give participants the opportunity to reflect upon their own photographs by writing responses to the six questions used in Wallerstein and Bernstein’s (1988) SHOWED method:
  - What do you see?
  - What is really happening?
  - How does this relate to our lives?
  - Why does this issue exist?
  - How can we become more empowered by understanding this issue?
  - What can we do to address this issue?

### **3) Gallery Walk**

- Invite participants to share the stories behind their own photographs, without interruption
- Facilitate group discussion, allowing participants to share questions, insights, and feelings evoked when viewing each photograph and hearing its accompanying story

### **4) Captioning and Titling**

- Once all photographs have been reviewed, encourage participants to assign a title and caption to their own works, taking into account both their individual reflections and group discussions

### **5) Pile Sorting and Labeling**

- Invite participants to categorize all photographs into mutually-agreed upon piles, considering the image, title, and caption as a single entity
- Participants should adhere to three basic criteria when pile-sorting:
  - All photographs should not be assigned to a single pile
  - All photographs should not be assigned to their own separate piles
  - Each photograph should only be assigned to one pile

### **6) Identifying Themes**

- Ask participants to collectively decide upon and apply a descriptive label to each pile produced, which accurately represents all photographs belonging to that set

### **7) Looking Ahead**

- Remind participants of next week's thematic prompt, as well as the meeting date, time and location
- Obtain participant input regarding future knowledge dissemination activities

Appendix E

**CONFIDENTIALITY AGREEMENT**

*The PhotoSTREAM Project:  
Supporting Transition-Readiness for Emerging Adults with Mental Health Challenges*

**Graduate Student Researcher**

Brianna Jackson, BScN, RN  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University



**Supervising Faculty Members**

Dr. Kim Jackson and Dr. Richard Booth  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University




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I understand that confidential information will be made known to me as a participant in *the PhotoSTREAM Project* conducted by the above study personnel of the Faculty of Health Sciences at Western University. I promise to respect the privacy of my peers, and agree never to disclose or transmit personal information discussed during focus groups to anyone outside of the research team, whether verbally, in writing, electronically, or by any other means. Furthermore, I agree not to refer to myself or fellow participants by full name or other personal identifier, such as email address, phone number, or physical description, during focus groups or interviews in which dialogue is audio-recorded.

---

*Participant Name*

---

*Participant Signature*

---

*Today's Date*

The researcher's signature below indicates that the confidentiality agreement has been described to the participant named above, and their written consent has been obtained.

---

*Researcher Name*

---

*Researcher Signature*

---

*Today's Date*

## Appendix F

### The Photo**STREAM** Project — Demographic Questionnaire

*This project is inclusive of all people, regardless of race, ethnicity, gender, sexual orientation, religious affiliation, or any other identity. Responses to the following questions are anonymous, and are for research purposes only.*

#### PART 1: GETTING TO KNOW YOU

1. With which of the following cultural/ethnic groups do you identify? Select all that apply.

- ☐ Asian (including Indian Subcontinent and Philippines)
- ☐ Black or African American (including Africa and Caribbean)
- ☐ Indigenous (including First Nations, Métis, Inuit)
- ☐ White or Caucasian (including Europe, North Africa, and Middle East)
- ☐ Multi-Ethnic
- ☐ Other (Please Specify): \_\_\_\_\_

2. Were you born in Canada?

- ☐ Yes
- ☐ No: How long have you lived in Canada? \_\_\_\_\_

3. How old are you in years? \_\_\_\_\_

4. What is your current relationship status?

- ☐ Single
- ☐ In a Relationship
- ☐ Married or Common Law
- ☐ Separated or Divorced
- ☐ Widowed
- ☐ I Prefer Not to Say
- ☐ Other (Please Specify): \_\_\_\_\_

5. What is your gender identity?

- ☐ Man
- ☐ Woman
- ☐ Genderqueer or Non-Binary
- ☐ Transgender
- ☐ Agender
- ☐ I Prefer Not to Say
- ☐ Other (Please Specify): \_\_\_\_\_

6. What is your sexual orientation?

- ☐ Asexual
- ☐ Bisexual
- ☐ Gay
- ☐ Heterosexual or Straight
- ☐ Lesbian
- ☐ Pansexual
- ☐ Queer
- ☐ Other (Please Specify): \_\_\_\_\_

7. Do you identify with any of the following religions? Select all that apply.

- ☐ Buddhism
- ☐ Christianity
- ☐ Hinduism
- ☐ Islam
- ☐ Judaism
- ☐ Native American
- ☐ Sikhism
- ☐ Inter-Faith/Non-Denominational
- ☐ Agnostic
- ☐ Atheist
- ☐ Other (Please Specify): \_\_\_\_\_

8. What is the highest level of education you have completed?

- ☐ Did Not Complete Secondary School
- ☐ Secondary School
- ☐ Community College or Apprenticeship
- ☐ University Undergraduate Degree
- ☐ University Graduate Degree or Beyond
- ☐ Other (Please Specify): \_\_\_\_\_

9. Which of the following describes your current employment status?

- ☐ Employed, Working Full-Time
- ☐ Employed, Working Part-Time
- ☐ Not Employed, Looking for Work
- ☐ Not Employed, Not Looking for Work
- ☐ Retired
- ☐ Unable to Work
- ☐ Other (Please Specify): \_\_\_\_\_

10. What is your estimated combined family/household income?

- ☐ Less than \$20,000
- ☐ \$20,000 to \$39,999
- ☐ \$40,000 to \$59,999
- ☐ \$60,000 to \$79,999
- ☐ \$80,000 to \$99,999
- ☐ \$100,000 or Greater
- ☐ I Prefer Not to Say

## PART 2: YOUR MENTAL HEALTH EXPERIENCE

1. Which of the following mental health services did you receive as a child/adolescent? Select all that apply.

- ☐ Crisis Services (immediate mental health support delivered in person, by phone, or online)
- ☐ Inpatient Psychiatric Services (mental health support requiring admission to a hospital or other clinical facility)
- ☐ Outpatient/Ambulatory Psychiatric Services (mental health support requiring ongoing follow-up in a community setting)
- ☐ Other (Please Specify): \_\_\_\_\_

2. Which of the following mental health services did you receive as an adult? Select all that apply.

- ☐ Crisis Services (immediate mental health support delivered in person, by phone, or online)
- ☐ Inpatient Psychiatric Services (mental health support requiring admission to a hospital or other clinical facility)
- ☐ Outpatient/Ambulatory Psychiatric Services (mental health support requiring ongoing follow-up in a community setting)
- ☐ Other (Please Specify): \_\_\_\_\_

3. How would you describe your transition from paediatric to adult mental health services?

- ☐ Very Positive
- ☐ Positive
- ☐ Neutral
- ☐ Negative
- ☐ Very Negative

4. How would you rate your current overall mental or emotional health?

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

5. If you were to require mental health support, do you feel that appropriate services are available and easily accessible to you?

- ☐ Yes — Available and Easily Accessible
- ☐ No — Available, but Not Easily Accessible
- ☐ No — Not Available
- ☐ Unknown

6. If services are available, but not easily accessible, which of the following pose potential barriers to receiving mental health support? Select all that apply.

- ☐ Competing Priorities (Ex. Childcare, Employment, Education ...)
- ☐ Cost
- ☐ Service Hours
- ☐ Stigma
- ☐ Transportation
- ☐ Wait Times
- ☐ Other (Please Specify): \_\_\_\_\_

7. Have mental health care providers been respectful of the personal identities you hold? For example: your ethnicity, religious affiliation, or sexual orientation.

- ☐ Strongly Agree
- ☐ Agree
- ☐ Neither Agree Nor Disagree
- ☐ Disagree
- ☐ Strongly Disagree



8. Do you feel that you are actively involved in decisions regarding your mental health care?

- ☐ Strongly Agree
- ☐ Agree
- ☐ Neither Agree Nor Disagree
- ☐ Disagree
- ☐ Strongly Disagree

9. Are family members, caregivers, and/or close personal friends included in discussions regarding your mental health care?

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Rarely
- ☐ Never

10. What three words would you use to describe Ontario's mental health care system?

\_\_\_\_\_

## Appendix G

### The PhotoSTREAM Project — Program Evaluation Questionnaire

*Please rate the following items based upon the degree to which you agree or disagree with the corresponding statement.*

- 1 = Strongly Disagree  
 2 = Disagree  
 3 = Neither Agree Nor Disagree  
 4 = Agree  
 5 = Strongly Agree

#### **Focus Group Content**

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| • I was well informed about the objectives of this focus group  | 1 | 2 | 3 | 4 | 5 |
| • The focus group lived up to my expectations                   | 1 | 2 | 3 | 4 | 5 |
| • Guiding questions and instructions were clear and helpful     | 1 | 2 | 3 | 4 | 5 |
| • The focus group activities/discussions stimulated my learning | 1 | 2 | 3 | 4 | 5 |
| • The handout materials were appropriate and useful             | 1 | 2 | 3 | 4 | 5 |

#### **Focus Group Design**

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| • Discussion topics were easily understood and engaging     | 1 | 2 | 3 | 4 | 5 |
| • The pacing of focus group discussions was appropriate     | 1 | 2 | 3 | 4 | 5 |
| • The number of focus group sessions was appropriate        | 1 | 2 | 3 | 4 | 5 |
| • The length of focus group sessions was appropriate        | 1 | 2 | 3 | 4 | 5 |
| • I felt safe and comfortable participating in focus groups | 1 | 2 | 3 | 4 | 5 |

#### **Facilitator**

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| • The facilitator was well-prepared and organized           | 1 | 2 | 3 | 4 | 5 |
| • The facilitator was supportive and encouraging            | 1 | 2 | 3 | 4 | 5 |
| • The facilitator created an environment of safe sharing    | 1 | 2 | 3 | 4 | 5 |
| • The facilitator was available for individual consultation | 1 | 2 | 3 | 4 | 5 |
| • The facilitator was knowledgeable, skilled, and effective | 1 | 2 | 3 | 4 | 5 |

### **Logistics**

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| • The orientation guide helped me to understand my role      | 1 | 2 | 3 | 4 | 5 |
| • The meeting location(s) was appropriate                    | 1 | 2 | 3 | 4 | 5 |
| • The meeting location(s) was easily accessible              | 1 | 2 | 3 | 4 | 5 |
| • Food and drinks provided met my dietary needs              | 1 | 2 | 3 | 4 | 5 |
| • I was kept informed of meeting dates, times, and locations | 1 | 2 | 3 | 4 | 5 |

### **Photovoice Method**

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| • I felt comfortable and supported in the photography process      | 1 | 2 | 3 | 4 | 5 |
| • Photos helped me to articulate my feelings and perspectives      | 1 | 2 | 3 | 4 | 5 |
| • Photos helped me to understand others' feelings and perspectives | 1 | 2 | 3 | 4 | 5 |
| • I would recommend the use of Photovoice for future studies       | 1 | 2 | 3 | 4 | 5 |
| • I would recommend participation in this study to a friend        | 1 | 2 | 3 | 4 | 5 |

### **Suggestions for Improvement**

What aspects of this study provided the greatest opportunity for sharing and learning?

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Which of the thematic prompts was most valuable and why?

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Which of the thematic prompts was least valuable and why?

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What discussion topics or activities should be included in future focus group sessions?

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What discussion topics or activities should be excluded from future focus group sessions?

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What changes would you make to enhance/improve your experience as a participant in this study?

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Do you have any additional feedback to share?

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## Appendix H

### *The PhotoSTREAM Project: Semi-Structured Exit Interview Guide*

#### **1) Qualitative Interview Introduction**

- Inform participant that interview will be approximately 30 minutes in length
- Inform participant that the purpose of the individual interview is to gain a richer understanding of their individual lived experience apart from the collective, and to illuminate the unique barriers and strengths that have influenced their mental health status during the transitional period
- Remind participant that responses to all questions will remain strictly confidential, and used for study purposes only
- Remind participant that interview dialogue will be audio-recorded
- Remind participant that their involvement in the interview process is voluntary — as such, they may elect to not answer any question(s), pause or end the interview at any time, or withdraw consent to audio record responses

#### **2) Interactions with the Mental Health System**

- Describe your experience with the mental health system as an adolescent.
  - How did you first access psychiatric services or supports — did you seek these out independently, were you accompanied by a friend or family member, or were you referred by a health care provider?
  - How would you describe the accessibility of psychiatric services and supports as an adolescent?
- Describe your experience with the mental health system as adult.
  - Did you transition directly from paediatric to adult care? Why or why not?
  - Did you feel the transition process was managed smoothly and that continuity of care was maintained? Why or why not?
- What do you feel were the major differences between paediatric and adult care?
  - Consider accessibility, treatment methods, caregivers... etc.

- What, if any, difficulties did you encounter when transitioning from paediatric to adult care?
  - What supports were available to you during the transition process?
  - Do you feel you had an advocate working on your behalf during the transition process, or do you feel you had to advocate for yourself?
- Without considering any limitations or restrictions, how would you improve the system for youth transitioning to adult mental health care?

### 3) Participation in the *PhotoSTREAM Project*

- Why did you choose to participate in this study?
- What expectations did you have for participation in this study?
  - How were those expectations met or not met?
  - Did you modify pre-existing expectations, or develop any new expectations as the study progressed?
- What is your opinion of the *Photovoice* method for addressing systemic barriers to mental health care for transitional aged youth?
  - Do you believe *Photovoice* is a "safe" method to use for exploring this issue?
- Do you feel that your thoughts, opinions, and beliefs were respected and incorporated throughout the *PhotoSTREAM Project*? Why or why not?
- What aspects of the *Photovoice* method do you believe provided the greatest opportunity for insights to be generated and discussed, and which parts could be improved upon?
  - Do you have any recommendations on how those improvements could be implemented?
- As a result of participation in this project, do you feel more connected to your community? Why or why not?
- As a result of participation in this project, do you feel more empowered to effect change as a young person and/or as a person with living with mental health challenges? Why or why not?

#### **4) Photo-Elicitation Discussion**

- Do you wish to share anything about the photographs you selected for printing that you did not have the opportunity to discuss during group sessions?
  - Describe the creative decisions you made (ex. angles, use of light, subjects)

#### **5) Closure**

- Thank participant for their continued involvement in the *PhotoSTREAM Project*
- Remind participant of upcoming optional analytical meeting

## Appendix I

### EXECUTIVE SUMMARY

*The PhotoSTREAM Project:  
Supporting Transition-Readiness for Emerging Adults with Mental Health Challenges*

#### **Graduate Student Researcher**

Brianna Jackson, BScN, RN  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University



#### **Supervising Faculty Members**

Dr. Kim Jackson and Dr. Richard Booth  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University




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Thank you for your participation in *The PhotoSTREAM Project*. As you may recall, the purpose of this study was to learn about the transition from paediatric to adult psychiatric services, and more specifically, the gaps or barriers that impact continuity of care, so that recommendations can be made for more effective and supportive transition policies and practices. This was carried out through engagement in personal photography, and three weekly focus group sessions involving individual reflection and collaborative discussion to aid in the discovery of overarching themes and patterns. Photographs aligning with three topics — (a) *the good*; (b) *the bad*; and, (c) *the vision* — served to highlight a broad spectrum of mental health experiences across the transitional period. Images provided a balanced perspective regarding the strengths and shortcomings of existing services available to the transitional-aged youth demographic, as well as opportunities for further growth, development, and innovation.

Through qualitative data analysis, the following study findings were obtained. Consistent with the Photovoice method, photographs elicited critical reflection and dialogue; thereby, revealing four overarching themes: (a) *Accessibility*; (b) *Coordination*; (c) *Independence*; and, (d) *Support*. Such findings contribute to contemporary nursing and interprofessional health literature advocating for the prioritization of emerging adults' unique psychosocial needs, through the creation, reformation, and evaluation of mental health-promoting policies and practices.

If you would like to read more about the results of this study or related research initiatives, please consult the resources below:

- <https://www.photostreamproject.org>
- <https://ir.lib.uwo.ca/etd/>

As a reminder, any information you shared with us will be kept strictly confidential. De-identified study data may be included in publications or presentations of study findings using a pseudonym, but direct quotes will never be shared without your consent.



Should you have any questions or concerns, please contact myself or the supervising faculty members listed above.

Your engagement in the research process is sincerely appreciated. Information gathered through this study may result in broader societal benefits, including enhanced awareness of emerging adult perspectives that may ultimately be integrated into mental health legislation and clinical practices.

Sincerely,

Brianna Jackson, BScN, RN

## Appendix J



**Date:** 21 February 2019

**To:** Dr. Kimberley Jackson

**Project ID:** 112971

**Study Title:** PhotoSTREAM: Supporting Transition-Readiness for Emerging Adults with Mental Health Challenges

**Application Type:** HSREB Initial Application

**Review Type:** Delegated

**Meeting Date / Full Board Reporting Date:** 12/March/2019

**Date Approval Issued:** 21/Feb/2019

**REB Approval Expiry Date:** 21/Feb/2020

Dear Dr. Kimberley Jackson

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

### Documents Approved:

Document Name	Document Type	Document Date	Document Version
Community Wellness Resources	Other Data Collection Instruments	18/Feb/2019	1
Confidentiality Agreement	Other Data Collection Instruments	18/Feb/2019	1
Demographic Questionnaire	Paper Survey	31/Oct/2018	1
Email Script	Email Script	18/Feb/2019	2
Executive Summary	End of Study Letter	31/Oct/2018	1
Focus Group Guide	Focus Group(s) Guide	18/Feb/2019	2
Interview Guide	Interview Guide	18/Feb/2019	2
LOU/Consent	Written Consent/Assent	18/Feb/2019	2
Orientation Guide	Other Data Collection Instruments	19/Feb/2019	1
Photo Consents	Other Data Collection Instruments	18/Feb/2019	1
Photo Release	Other Data Collection Instruments	18/Feb/2019	1
Program Evaluation	Paper Survey	31/Oct/2018	1
Recruitment Poster	Recruitment Materials	18/Feb/2019	2
Research Protocol	Protocol	18/Feb/2019	2

### Documents Acknowledged:

Document Name	Document Type	Document Date	Document Version
References	References	31/Oct/2018	1

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C,

Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

A solid black rectangular box used to redact a signature.

*Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).*

Appendix K

**PHOTOGRAPH CONSENT FORM (INDIVIDUAL)**

*The PhotoSTREAM Project:  
Supporting Transition-Readiness for Emerging Adults with Mental Health Challenges*

**Graduate Student Researcher**

Brianna Jackson, BScN, RN  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University



**Supervising Faculty Members**

Dr. Kim Jackson and Dr. Richard Booth  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University




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By signing below, you give your consent to be photographed as part of *the PhotoSTREAM Project*, a research study conducted by the above personnel of the Faculty of Health Sciences at Western University. Your name, or other personal identifying information will not accompany published photographs.

If you have questions about your rights as a research participant or the conduct of this study, you may contact *the Office of Human Research Ethics* at [REDACTED] or [REDACTED].

☐ Yes    ☐ No    I understand that my face, body, or personal property are recognizable in the photographs taken by the undersigned photographer.

☐ Yes    ☐ No    I further authorize that these photographs may be published by Western University for research purposes.

\_\_\_\_\_  
*Participant Name*

\_\_\_\_\_  
*Participant Signature*

\_\_\_\_\_  
*Today's Date*

The photographer's signature below indicates that the above agreement has been described to the participant named above, and their written consent has been obtained.

\_\_\_\_\_  
*Photographer Name*

\_\_\_\_\_  
*Photographer Signature*

\_\_\_\_\_  
*Today's Date*

**PHOTOGRAPH CONSENT FORM (ORGANIZATION)**

*The PhotoSTREAM Project:  
Supporting Transition-Readiness for Emerging Adults with Mental Health Challenges*

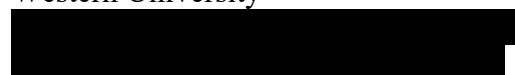
**Graduate Student Researcher**

Brianna Jackson, BScN, RN  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University



**Supervising Faculty Members**

Dr. Kim Jackson and Dr. Richard Booth  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University



By signing below, you give your consent to have personnel or property of your organization photographed as part of *the PhotoSTREAM Project*, a research study conducted by the above personnel of the Faculty of Health Sciences at Western University. The name of your organization, or other identifying information will not accompany published photographs.

If you have questions about your rights as a research participant or the conduct of this study, you may contact *the Office of Human Research Ethics* at [redacted] or [redacted].

☐ Yes    ☐ No    I understand my organization's personnel or property are recognizable in the photographs taken by the undersigned photographer.

☐ Yes    ☐ No    I further authorize that these photographs may be published by Western University for research purposes.

_____ <i>Organization Name</i>	_____ <i>Organization Location</i>	_____ <i>Today's Date</i>
_____ <i>Representative Name</i>	_____ <i>Representative Title</i>	_____ <i>Representative Signature</i>

The photographer's signature below indicates that the above agreement has been described to the organizational representative named above, and their written consent has been obtained.

_____ <i>Photographer Name</i>	_____ <i>Photographer Signature</i>	_____ <i>Today's Date</i>
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## Appendix L

### **COMMUNITY WELLNESS RESOURCES**

#### **Action Canada Access Line**

- A 24-hour Canada-wide toll-free number that provides information on sexual and reproductive health as well as referrals to clinics and hospitals that offer health services, including counselling for abortion and pro-choice pregnancy options.
- (888) 642-2725
- [sexualhealthandrights.ca](http://sexualhealthandrights.ca)
- [access@sexualhealthandrights.ca](mailto:access@sexualhealthandrights.ca)

#### **Addiction Services of Thames Valley**

- A community-based service that provides screening, assessment, referrals, and addiction treatment services for persons who are concerned about substance use, internet/gaming disorders, or gambling problems.
- (519) 673-3242
- [adstv.ca](http://adstv.ca)
- [start@adstv.ca](mailto:start@adstv.ca)

#### **AIDS and Sexual Health Infoline**

- A province-wide, free, anonymous service staffed by professional, multidisciplinary, and multicultural counsellors who offer anonymous and non-judgmental counselling, and current, accurate and detailed information and support.
- (800) 668-2437

#### **Anova (formerly the Sexual Assault Centre London and Women's Community House)**

- Services provided include: sexual violence counselling, a 24-hour helpline, emergency short-term shelters for women and their children experiencing abuse, public education training and workshops, violence prevention youth programming, second stage housing, and transitional outreach services.
- (800) 265-1576
- [anovafuture.org](http://anovafuture.org)

#### **Anova Sexual and Domestic Violence Helpline**

- A 24-hour help line for issues related to sexual violence and domestic violence that is open to all genders.
- (519) 642-3000

### **Canadian Mental Health Association (CMHA) Middlesex**

- Provides community mental health services, housing supports, education, and drop-in community programs across London, Middlesex, Strathroy, Exeter, and Goderich. Crisis services include a 24/7 walk- in mental health and addictions crisis centre, and you can also call Reach Out, a 24/7 mental health and addictions information, support, and crisis helpline.
- (519) 434-9191
- (866) 933-2023 – Reach Out
- cmhamiddlesex.ca
- info@cmhamiddlesex.ca

### **Can-Voice**

- A peer support, self-help organization for the education and empowerment of consumers/survivors of the mental health system.
- (519) 434-8303
- can-voice.org
- canvoice@gtn.net

### **CONNECT for Mental Health**

- A not-for-profit peer support organization run by and for individuals who have been affected by mental illness; trained peer support volunteers and facilitators provide a variety of services in London to all ages including youth, young adults, and seniors, with over 50 different peer led workshops and groups, such as Wellness Recovery Action Planning and Peer Zone.
- (519) 679-4040
- connectformh.ca
- message@connectformh.ca

### **Daya Counselling Centre**

- Provides therapeutic counselling services to individuals, families, and couples and ensures that the cost of counselling is not a barrier to access – fees are based on income and Daya is committed to ensuring no one is turned away due to their ability to pay for service.
- (519) 434-0077
- dayacounselling.on.ca
- info@dayacounselling.on.ca

### **Drug and Alcohol Helpline**

- A live 24/7 confidential helpline service that provides information about drug and alcohol addiction services available in Ontario.
- (800) 565-8603
- drugandalcoholhelpline.ca

**Good2Talk**

- A free, confidential and anonymous helpline providing professional counselling, information and referrals for mental health, addictions and well-being to post-secondary students.
- (866) 925-5454
- [good2talk.ca](http://good2talk.ca)

**LGBT Youth Line**

- A toll-free service providing support, information, and referrals specific to your concerns; the LGBT Youth Line volunteers are lesbian, gay, bisexual, transgender, transsexual, two-spirit, or queer.
- (800) 268-9688
- [youthline.ca](http://youthline.ca)

**LGBT2Q+ Resources of the Middlesex-London Health Unit**

- A directory of LGBT2Q+ friendly resources that are maintained by The LGBT2Q+ Network of London and Area. Resources include counselling and therapists, esthetic services, legal services, social services, support groups, and more.
- (519) 663-5446
- [healthunit.com/lgbtq-resources](http://healthunit.com/lgbtq-resources)

**London Abused Women's Centre**

- Offers abused, prostituted, and sex-trafficked women and girls (over the age of 12) hope and help for their hurt through the provision of advocacy, long-term counselling, and support services in a safe, non-crisis, non-residential setting.
- (519) 432-2204
- (519) 642-3000 – Abused Women's Helpline
- [lawc.on.ca](http://lawc.on.ca)
- [info@lawc.on.ca](mailto:info@lawc.on.ca)

**Mental Health Helpline**

- A live 24/7 confidential helpline that provides information about mental health services available in Ontario.
- (866) 531-2600
- [healthunit.com/sexual-health](http://healthunit.com/sexual-health)

**Middlesex-London Health Unit Sexual Health**

- Provides a confidential and comfortable environment for discussing sexual health questions and concerns, and offers free testing and treatment, the morning after pill, pregnancy testing, and low cost birth control.
- (519) 663-5446
- [healthunit.com/sexual-health](http://healthunit.com/sexual-health)



**Mission Services of London**

- Through a network of five branch locations, provides food, clothing, shelter, crisis assistance, addiction treatment, mental health programs and support services.
- (519) 433-2807
- [missionservices.ca](http://missionservices.ca)

**Mood Disorders Association of Ontario (MDAO)**

- Runs peer support and recovery programs for individuals and families living with depression, anxiety or bipolar disorder – provides a supportive toll-free telephone line, one on one peer support and counselling services.
- (866) 363-6663
- [mooddisorders.ca](http://mooddisorders.ca)

**N'Amerind Friendship Centre**

- Assists members of the London urban indigenous community through the delivery of programs and services to support dealing with the challenges of life – employment and education counselling, healing and wellness, and addiction support.
- (519) 672-0131
- [namerind.on.ca](http://namerind.on.ca)

**Regional Sexual Assault and Domestic Violence Treatment Centre**

- Available 24/7 through St. Joseph's Hospital in London, provides care for women, children, and men experiencing sexual assault and/or domestic violence living in Oxford, Elgin, Huron-Perth, and Middlesex counties.
- (519) 646-6100, ext 64224
- [sjhc.london.on.ca/sexualassault](http://sjhc.london.on.ca/sexualassault)

**The Salvation Army Centre of Hope**

- A Christian organization that provides hostel services, a housing stability bank, substance abuse counselling, a food bank, and spiritual care.
- (519) 661-0343
- [centreofhope.ca](http://centreofhope.ca)

**Southwest Ontario Aboriginal Health Access Centre (SOAHAC)**

- Provides free, culturally safe, holistic health and wellness services to the indigenous community across southwestern Ontario. Mental health and addictions services include counselling, screening and assessment, some crisis intervention, referral, support services, groups, addictions support and referral, case management, social work, advocacy and follow-up, and the development and monitoring of individual wellness plans.
- (519) 672-4079
- [soahac.on.ca/service/London](http://soahac.on.ca/service/London)

**Unity Project**

- Offers a home-like emergency shelter for men, women and youth, by providing crisis support, emergency shelter, transitional housing, housing support, and drop-in counselling services.
- (519) 433-8700, ext 0
- [unityproject.ca](http://unityproject.ca)
- [info@unityproject.ca](mailto:info@unityproject.ca)

# Appendix M

## PHOTOGRAPH RELEASE AGREEMENT

*The PhotoSTREAM Project:  
Supporting Transition-Readiness for Emerging Adults with Mental Health Challenges*

### Graduate Student Researcher

Brianna Jackson, BScN, RN  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University  
[Redacted]

### Supervising Faculty Members

Dr. Kim Jackson and Dr. Richard Booth  
Arthur Labatt Family School of Nursing  
Faculty of Health Sciences  
Western University  
[Redacted]

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By signing below, you give authorization for the above personnel of the Faculty of Health Sciences at Western University to utilize your photographs for research purposes, as part of *the PhotoSTREAM Project*.

If you have questions about your rights as a research participant or the conduct of this study, you may contact *the Office of Human Research Ethics* at [Redacted] or [Redacted].

- ☐ Yes    ☐ No    I agree that all of the images I photographed and shared with study personnel via OneDrive may be used for print and/or multimedia publishing by Western University.
- ☐ Yes    ☐ No    I agree that Western University has the unconditional right to use, publish, reproduce, alter, or distribute the photographs for non-commercial purposes only.
- ☐ Yes    ☐ No    I agree that copyrights and other intellectual property rights concerning these photographs belong to Western University.

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*Participant Name*

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*Participant Signature*

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*Today's Date*

The researcher's signature below indicates that the above agreement has been described to the participant named above, and their written consent has been obtained.

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*Researcher Name*

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*Researcher Signature*

---

*Today's Date*

## CURRICULUM VITAE

*Brianna Jackson, BScN, RN*

### EDUCATION

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- 2017/09 – 2019/07    **Master of Science in Nursing (MScN)    GPA: 4.00**  
Nursing Leadership in Health Promotion and Advanced Nursing Practice  
University of Western Ontario
- Thesis: Exploring the Mental Health Care Experiences of Youth  
Transitioning from Paediatric to Adult Psychiatric Services Using the  
PhotoVoice Method: A Participatory Analysis of the PhotoSTREAM  
Project*
- Supervisors: Dr. Kim Jackson and Dr. Richard Booth
- 2013/09 - 2017/06    **Bachelor of Science in Nursing (BScN)    GPA: 3.98**  
University of Western Ontario
- Integrative Practicum: Adolescent Psychiatry, St. Joseph's Healthcare  
London

### SCHOLARSHIPS AND AWARDS

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- 2019/04    *Master's Student Award of Excellence*  
Council of Ontario University Programs in Nursing
- 2019/03    *Research in Mental Health Nursing Award - \$1,500 (CAD)*  
Registered Nurses' Foundation of Ontario
- 2019/03    *Nursing Doctoral Scholarship - \$101,575 (USD)*  
Yale University
- 2018/09    *Canada Graduate Scholarship, Master's - \$17,500 (CAD)*  
Canadian Institutes of Health Research
- 2018/08    *Graduate Student Award - \$3,000 (CAD)*  
Irene E. Nordwich Foundation
- 2017/09    *Ontario Graduate Scholarship - \$15,000 (CAD)*  
University of Western Ontario
- 2017/05    *Registered Nurses' Foundation of Ontario Tribute Award - \$500 (CAD)*  
Registered Nurses' Foundation of Ontario

## **PUBLICATIONS**

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- 2019/03 Dr. Tara Mantler, Dr. Kimberley T. Jackson, Edmund J. Walsh, **Brianna Jackson**, Jessi R. Baer, Sarah Parkinson. (2019). *Promoting Attachment Through Healing (PATH): Results of a Retrospective Feasibility Study*. Journal of Psychosomatic Obstetrics and Gynecology, Submitted.
- 2019/03 Dr. Kimberley T. Jackson, Dr. Tara Mantler, **Brianna Jackson**, Edmund Walsh, Jessi R. Baer, Sarah Parkinson. (2019). *Exploring Mothers' Experiences of Trauma and Violence-Informed Cognitive Behavioural Therapy Following Intimate Partner Violence: A Qualitative Case Analysis*. Journal of Psychosomatic Obstetrics and Gynecology, Submitted.
- 2018/05 Dr. Kimberley T. Jackson, Sarah Parkinson, **Brianna Jackson**, Dr. Tara Mantler. (2018). *Examining the Impact of Trauma-Informed Cognitive Behavioral Therapy on Perinatal Mental Health Outcomes Among Survivors of Intimate Partner Violence (The PATH Study): Protocol for a Feasibility Study*. Journal of Medical Internet Research, 7(5). doi: 10.2196/resprot.9820

## **PRESENTATIONS**

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- 2019/05 Breakout Presentation: *The PhotoSTREAM Project: Supporting Transition-Readiness in Emerging Adults with Mental Health Challenges Using the PhotoVoice Method*  
Child Health Symposium  
London, Ontario
- 2019/04 Media Interview: *The PhotoSTREAM Project*  
CTV News  
London, Ontario
- 2019/03 Poster Presentation: *The PhotoSTREAM Project*  
Transition Age Protocol Community Implementation Team (TAPCIT)  
Open House  
London, Ontario
- 2018/11 Poster Presentation: *Establishing a Web-Based Peer Support Network for Youth Experiencing Mental Health Challenges*  
Centre for Innovation in Campus Mental Health (CICMH) Conference  
Toronto, Ontario
- 2018/09 Oral Paper Presentation: *PATH: Promoting Attachment Through Healing*  
Nursing Network on Violence Against Women International (NNVAWI) Annual Conference  
Niagara-on-the-Lake, Ontario

## **EMPLOYMENT**

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2018/12 – 2019/07	Invigilator Arthur Labatt Family School of Nursing University of Western Ontario
2018/07 – 2019/07	Registered Nurse Interventionist iHEAL Clinical Trial University of Western Ontario and the Public Health Agency of Canada
2017/08 – 2019/07	Graduate Research Assistant Arthur Labatt Family School of Nursing University of Western Ontario
2017/11 – 2019/03	Registered Nurse Child and Adolescent Inpatient Mental Health London Health Sciences Centre
2018/02 - 2018/06	Registered Nurse Adolescent Psychiatry and Dual Diagnosis Program St. Joseph's Health Care London
2017/08 - 2018/01	Mental Health Crisis Counsellor Crisis Response Team Canadian Mental Health Association of Middlesex